

# **Developing Content for Skills and Support Interventions for Mothers and Fathers of Children with Feeding Disorders**

Avital Pearlman

Doctoral Thesis

Doctorate in Clinical Psychology

## **Acknowledgements**

In writing my doctoral thesis I have learnt a lot. Not only about the kindness and patience of those around me, but the generosity of supervisors and colleagues in offering their ongoing support. I owe particular thanks to Dr Rachel Bryant-Waugh for offering me her time and in helping me to structure and think about how to conduct this research, as well as joining me at panel meetings. With her support I have been given the opportunity to conduct this research in a national feeding disorder service have had the opportunity to learn from her and the rest of the team's expertise. I will always be grateful to Rachel and the team at GOSH. A special thank you to Dr Emma Piepenstock who offered me her time and skills. I would also like to thank my supervisor, Dr Matthew Jones-Chesters, for his guidance and patience.

I cannot go without thanking my family, who have supported me throughout conducting my research, during which time I had a daughter, Sophia, whom they have helped care for whilst I have been writing my thesis. There have been struggles, as my daughter experienced many of the difficulties I have written about, often making it harder to put pen to paper. However, with the support of my husband and my parents, we got there in the end. Thank you.

## **TABLE OF CONTENTS**

1. ABSTRACT	11
2. INTRODUCTION	12
2.1. Background	12
2.2. Feeding Disorders of Early Childhood / Avoidant/Restrictive Food Intake Disorder (ARFID)	14
2.3. Aetiology of Feeding Disorders	16
2.3.1. Organic versus Non-Organic Causes of Feeding Disorders	17
2.3.2. Developmental Delay and Feeding Disorders	18
2.3.3. Autism Spectrum Disorders and Feeding	19
2.3.4. Relational Aspects of Feeding Disorders: The Mother-Child Relationship	21
2.3.5. Attachment and Early Feeding Relationships	22
2.3.6. Moving Toward a Relational/Triadic Model of Feeding	23
2.3.7. Fathers and Feeding	24
2.4. The Impact of Feeding Disorders on Parental Mental Health	25
2.4.1. Parental Stress and Coping	26
2.4.2 Anxiety in Parents of Children with Feeding Disorders	27
2.4.3. Parental Depression and Loneliness in the Context of Childhood Feeding Disorders	28
2.5. Treatment for Feeding Disorders/ARFID	30
2.5.1. Moving Toward Systemic Intervention	30
2.5.2. Current Treatment of Feeding Disorders in Early Childhood	31
2.5.3. Parent Groups for Children with Feeding/ Eating Disorders	32

2.6. Rationale for the Current Study	35
2.6.1. Research Aims	37
3. METHODOLOGY	37
3.1. Design	37
3.1.1. Materials	
3.1.1.1 Parenting Stress	39
3.1.1.2 Depression	41
3.1.1.3 Anxiety	42
3.1.1.4 Loneliness	43
3.1.1.5 Coping	44
3.1.1.6 Feeding Disorder Severity	46
3.1.1.7 Demographic Questionnaire	46
3.2 Ethical Considerations	47
3.2.1 Possible Distress Caused and Identification of Further Problems	47
3.2.2 Storage of Data	48
3.2.3 Confidentiality and Consent	48
3.2.4 Ethical Approval	49
3.3 Procedure	49
3.3.1 Participant Recruitment	49
3.3.2 Inclusion Criteria	51
3.3.3 Exclusion Criteria	52
3.4. Participant Information	52
3.4.1. Demographic Information and Raw Scores	52
3.4.1.1. Child factors	52
3.4.1.2. Developmental Delay & Autism	53

3.4.1.3. Medical Problems, Tube Feeding & Emotional- Behavioural Factors	53
3.4.1.4. Maternal Factors	53
3.4.1.5. Paternal Factors	53
3.4.1.6. Joint Parent Factors	54
3.4.1.7. Summary	55
3.5. Data Analysis	56
4. RESULTS	59
4.1. Exploratory Data Analysis	59
4.2. Summary of exploratory data analysis	62
4.3. Results of Research Aim One	62
4.3.1. Summary of Research Aim One	65
4.4. Results of Research Aim Two	66
4.4.1. Beck Depression Inventory	67
4.4.2. BAI	67
4.4.3. Active Coping Subscale – Brief COPE	67
4.4.4. Passive Coping Subscale - Brief COPE	67
4.4.5. UCLA Loneliness Scale	68
4.4.6. Parent Stress Inventory – Short Form	68
4.4.7. Summary of Research Aim Two	68
4.5. Results of Research Aim Three	68
4.5.1. Predictors for Mother Depression	69
4.5.2. Predictors for Father Depression	70
4.5.3. Predictors for Mother and Father Anxiety	71
4.5.4. Predictors for Active Coping in Mothers	71
4.5.5. Predictors for Passive Coping in Mothers	71
4.5.6. Predictors for Father Active Coping	72

4.5.7. Predictors for Passive Coping in Fathers	72
4.5.8. Predictors for Loneliness in Mothers	72
4.5.9. Predictors for Loneliness in Fathers	73
4.5.10. Predictors for Parent Stress in Mothers	73
4.5.11. Predictors for Parenting Stress in Fathers	74
4.5.12. Summary of Research Aim Three	74
 5. DISCUSSION	 77
5.1. Overview	77
5.1.1. Overview of Child Factors	78
5.1.2. Overview of Mother Sample	78
5.1.3. Overview of Father Sample	79
5.1.4. Overview of Parent Sample (joint factors)	79
 5.2. Discussion of Research Aim One	 79
5.2.1. Depression	79
5.2.2. Anxiety	81
5.2.3. Coping	81
5.2.4. Social Isolation	82
5.2.5. Parent Stress	83
5.2.6. Summary of Research Aim One	83
 5.3. Discussion of Research Aim Two	 84
 5.4. Discussion of Research Aim Three	 85
5.4.1. Predictors for Mother and Father Scores across the Five Variables	86
5.4.1.1. Depression (Mothers)	86
5.4.1.2. Depression (Fathers)	87
5.4.1.3. Coping (Mothers)	88
5.4.1.4. Coping (Fathers)	89
5.4.1.5. Loneliness (Mothers)	89
5.4.1.6. Loneliness (Fathers)	91

5.4.1.7. Parent Stress (Mothers and Fathers)	91
5.4.2. Summary of Research Aim Three	92
5.5. Limitations	92
5.5.1. Measures	92
5.5.2. Sampling Procedure	94
5.6. Research Implications	96
5.6.1. Clinical Implications	96
5.6.2. Future Research	97
5.7. Summary/Conclusions	99
6. REFERENCES	102

## **TABLE OF CONTENTS – TABLES AND FIGURES**

### **TABLES**

#### **3. METHODOLOGY**

3.1: Percentage of children reported to have a developmental delay and the severity of the delay	53
3.2: Religious beliefs of the parent sample	54
3.3: Recorded ethnicities of the parent sample	54
3.4: Marital status of parent sample	55

#### **4. RESULTS**

4.1. Table to Show Age of Parent Participants, Parent Scores, Skewness and Kurtosis	59
4.2. Table to Show Shapiro-Wilk Test for Normality	60
4.3. Table to Show 'Normal' Scores of Transformed Data for Further Statistical Analysis	61
4.4. Table to Show Matched Mother and Father Raw Scores on the Five Variables	63
4.5. Table to show the mean scores of mothers and fathers on each of the variables and how many parents showed scores above cut off.	64
4.6. Table to Show the Difference between Mother and Father Scores on each of the Identified Variables using a Wilcoxon's Signed Ranks Test	66
4.7. Showing predictors accounting for large amounts of variance in mothers' and fathers' responses on each of the identified variables and the amount of variance accounted for.	74



## **FIGURES (Appendix 10)**

Figure 4.1. Histogram to Show the Spread of Mother Age within the Research Sample	150
Figure 4.2. Histogram to Show the Spread of Father Age within the Research Sample	150
Figure 4.3. Histogram showing the distribution of Mother's scores on the Beck Depression Inventory	151
Figure 4.4. Histogram showing the distribution of father's scores on the BDI	151
Figure 4.5. Histogram Showing the Distribution of Mother Scores on the Beck Anxiety Inventory	152
Figure 4.6. Box Plot Diagram Showing Outliers within Mother BAI Scores	152
Figure 4.7: Histogram to Show the Distribution of Mother Active Coping Scores on the Brief COPE	153
Figure 4.8. Histogram Showing the Distribution of Father Active Coping Scores on the Brief COPE	153
Figure 4.9. Histogram to Show the Distribution of Mother Passive Coping Scores on the Brief COPE	154
Figure 4.10. Histogram to Show the Distribution of Father Passive Coping Scores on the Brief COPE	154
Figure 4.11. Histogram to Show the Distribution of Mother Loneliness Scores on the UCLA Loneliness Scale	155
Figure 4.12. Histogram to Show the Distribution of Father Loneliness scores on the UCLA Loneliness Scale	155
Figure 4.13. Histogram to Show the Distribution of Total Mother Parenting Stress Scores on the Parent Stress Index - SF	156
Figure 4.14. Histogram to Show the Distribution of Total Father Parenting Stress Scores on the Parent Stress Index - SF	156

<b>APPENDICES</b>	122
Appendix 1. Study Protocol	122
Appendix 2. Participant Information Sheet	128
Appendix 3. Consent Form	131
Appendix 4. Questionnaire Pack	132
Appendix 5. Demographic Questionnaire	140
Appendix 6. BPFAS	141
Appendix 7. UEL Ethical Approval	142
Appendix 8. GOSH Ethical Approval	143
Appendix 9. NHS Ethical Approval	146
Appendix 10. Exploratory Data Histograms	150

## 1. ABSTRACT

The present study was designed to gather information on how both mothers and fathers are impacted by their child's feeding disorder as a precursor to the development of skills and support groups that are useful and relevant to both parents. Recent studies highlight that fathers play an important role in a child's upbringing and both impact and are impacted by their child's feeding disorder (Gueron-Sela et al., 2011; Piepenstock, 2010). Feeding disorders are treated systemically and therefore need to include both parents in the child's treatment. This study used a quantitative, questionnaire based, independent groups design, where mother and father scores were compared on a range of variables identified as being relevant to feeding disorders. These included; anxiety, depression, loneliness, parenting stress and coping. A further aim of the study was to determine whether child and parent characteristics lead to different outcomes on the identified variables and therefore highlight which aspects need to be given greater weighting in potential group interventions. Thirty-six matched mother-father pairs completed the questionnaires in full. A series of calculations, Wilcoxon Rank Tests and regressions were conducted. Whilst mother scores were higher on each of the variables, it was of note that equal numbers of mothers and father scored above clinical cut-off for depressive symptoms (six of each), indicating that parental mental health should be addressed within support groups. A further finding was that a significant proportion of both mothers and fathers report feeling isolated when parenting a child with feeding disorders, this too should be addressed in groups, enabling communication within and between parent couples. This study highlighted the difficulty of both parents attending a weekday service; therefore perhaps innovative means of support could be offered, such as internet-groups facilitated by a clinician. Other findings of interest were that age of child and presence of developmental delay/Autism impacted on the severity of depressive symptoms and loneliness in both parents. It may therefore be useful to consider child age and presence of developmental delay when setting up skills and support groups. It is hoped that a parent skills and support group will be developed and trialled using information from this study.

## **2. INTRODUCTION**

### **2.1. Background**

Throughout this chapter, the origins, aetiology, experiences of families with children with feeding disorders and treatments are explored in order to support the development of skills and support groups for parents. The current understanding is that mothers are at the core of the feeding relationship and that this is reflected to some extent in the treatment offered, an argument has been put forward indicating why both parents should be targeted for intervention. The aim of this study is to develop a better understanding of how both parents are affected by their child's feeding disorder and in turn what would be useful to include in a group skills and support intervention. A brief overview of feeding disorders is given below and each area will be discussed in greater detail further on the chapter.

The search engines used within this study were; PsycINFO, PubMed, Wiley Online Library, Elsevier, Science Direct, EBSCOhost and Medline. Search terms included; feeding disorders of early childhood, failure to thrive, fathers and feeding, attachment and feeding, mothers and feeding, relational models of feeding, psychological impact of feeding disorders on parents, developmental delay and feeding disorders, organic causes of feeding disorders, systemic treatment of feeding disorders and group intervention in feeding disorders.

The incidence of feeding difficulties in typically developing children is approximately 30 per cent (Blissett & Harris, 2002) rising to 80 per cent in children with developmental disabilities (Manikam & Perman, 2000). The act of feeding from the earliest moments is central to both the development of the child and the relationship between the parent and infant, with most studies commonly citing the mother as the parent most strongly linked to childhood feeding (Chatoor et al., 1998; Coulthard & Harris, 2003).

Whilst feeding is often seen as a fundamental aspect of development, it is a complex act, where a number of factors have to fall into place for the child to feed successfully (Satter, 1990). Feeding can be interrupted by: bio-medical issues such as gastro-intestinal problems; feeding related trauma; psychological, behavioural or developmental delays; and difficulties in the feeding relationship between parent (predominantly mothers) and child (Linscheid and Murphy, 1999).

There are few studies researching how both mothers and fathers are impacted by their child's feeding disorder. Most studies research the mother-child relationship (Chatoor et al; 1998; Coulthard & Harris, 2003; Lindberg et al; 1996). As fathers are rarely included in research, they remain a largely untapped resource.

There is a wealth of research identifying the significance of the mother-child dyad (Micali et al., 2009, Chatoor, 1997). However, Piepenstock (2010) highlights that fathers are also significantly impacted by their child's feeding disorder expressing heightened levels of stress as compared to controls. Fathers are no longer sole breadwinners and have a greater role in parenting (Newton et al., 2006). If both parents are given strategies to cope with the stress of having a child with a feeding disorder it encourages consistency in parental intervention, and a stronger foundation from which to help the child.

The central aim of this study is to gain a greater understanding as to how both parents are impacted by having a child with a feeding disorder in order to inform skills and support groups. A further aim is to investigate whether mothers and fathers are impacted differently according to the age of the child and the perceived origin and severity of the feeding disorder. It is hoped that the skills and support groups will encourage parents to understand the various contributing factors to the maintenance of their child's feeding disorder; to develop strategies to ensure that they look after their own mental health in order to better enable them to support their child.

This research hopes to add to the literature by developing an understanding as to how having a child with a feeding disorder impacts both mothers and fathers and offering a preliminary step in establishing an intervention that includes both parents to support the child in overcoming feeding difficulties.

## **2.2. Feeding Disorders of Early Childhood/ Avoidant/Restrictive Food Intake Disorder**

Children who are given a diagnosis of feeding disorders display a range of behaviours, including: food refusal; selective eating to the extent that they are nutritionally compromised; significant aversions to taste, texture or colour of foods; challenging behaviour at mealtimes (e.g. gagging or regurgitating food as a learned behavioural response to feeding; getting up from the table; clamping their mouth shut and behavioural outbursts). For these to be severe enough to meet diagnosis for a feeding disorder/ARFID, the criteria described below must be met.

The previous DSM-IV-TR (APA, 2000) definition of 'Feeding Disorders of Infancy and Early Childhood' has recently been reclassified in the more recent DSM-V (APA, 2013) to 'Avoidant/Restrictive Food Intake Disorder' (ARFID). The earlier DSM-IV diagnostic criteria were rarely met as the disorder should not overlap with an underlying medical condition and one of the main diagnostic criteria was failure to gain weight or significant weight loss over at least one month. Recent research identified that very few children met the diagnostic criteria for a feeding disorder, even within specialist feeding disorder services (Bryant-Waugh & Piepenstock, 2008). This was due to a previous medical condition being at the root of the disturbance, or the child maintaining their weight due to artificial feeding. At the time this research was conducted, the DSM-V had not yet been published, therefore the term 'feeding disorders' will be used to describe the symptoms of the children presenting at the service. The children of the parents in this study were considered to meet clinical diagnostic criteria for feeding disorders (reflective

of the current DSM-V classification). Both the DSM-IV-TR and the DSM V classifications are detailed below.

DSM-IV-TR – Feeding Disorders of Infancy and Early Childhood (APA, 2000):

To meet the DSM-IV-TR diagnostic criteria for feeding disorders the child needed to meet the following diagnostic criteria:

1. Ongoing failure to eat adequate amounts of food that leads to either significant weight loss or persistent failure to gain weight (must be for at least one month).
2. The disturbed feeding cannot be due to an associated medical or gastrointestinal condition.
3. The feeding disturbance cannot be better explained by a lack of food available to the child or by a different mental disorder either in the parent or child.
4. The child must develop the disorder prior to 6 years of age.

DSM-V – ARFID :

To meet the DSM-V diagnostic criteria for ARFID (APA, 2013), the child must show signs of disturbed feeding or eating that leads to the child not meeting adequate nutritional or energy intake and must display one or more of the following symptoms:

1. Ongoing failure to meet expected weight gain or growth or a significant loss of weight.
2. Nutritional deficiency that is significant enough to impact day-to-day functioning.
3. The need for enteral feeding or dependence on high calorie/protein nutritional supplements.
4. There is a noticeable impact on the child's psychosocial functioning.

Furthermore the issues with which the person is presenting cannot be explained by a lack of access to food, cultural practices, cannot be better explained by an eating disorder (Anorexia/Bulimia Nervosa) and there is no reference to weight or shape concerns. The feeding disturbance cannot be associated with a medical/mental health condition, however if it does occur in these circumstances, the feeding behaviours must exceed what is usually

associated with the symptoms of the condition and further clinical support is needed.

It should be noted that within the feeding disorder literature, terms such as 'failure to thrive' and 'feeding problems' are also used under the feeding disorder umbrella. Children displaying 'failure to thrive' exhibit inhibited growth and development as compared to their peers (Frankl & Zeisel, 1988); this is often due to the presence of a feeding disturbance (Wright & Birks, 2000).

Owing to the complex presentation of feeding disorders, it is important to consider their possible origins in order to have a better understanding as to where intervention would be useful. The aetiology of feeding disorders is therefore discussed in the following section.

### **2.3. Aetiology of Feeding Disorders**

A recent review by Bryant-Waugh et al (2010) highlights the difficulty in both categorising feeding disorders and distinguishing whether the disturbance is of organic or non-organic origin. Feeding disorders are often multi-factorial as they frequently involve medical, emotional, behavioural and relational disturbances (Rommel et al., 2003). There appears to be a significant overlap across the possible causes of feeding disorders, as it is likely that there will be an emotional and behavioural impact on both the child and family irrespective of the origin of the disturbance (Davies et al., 2006), likely exacerbating the child's feeding difficulties.

Davies et al (2006) argued that the DSM-IV-TR definition did not place sufficient emphasis on the interpersonal aspects of feeding and should be re-categorised as a relational disorder existing between the child and parent/care-giver. Bryant-Waugh and Piepenstock (2008) noted that feeding by implication involves an interaction between the child and caregiver, as opposed to eating, which occurs on an individual basis. Particular parental traits and styles are more considered to be apparent in children with feeding disorders (Bryant-Waugh et al, 2010), for example mothers there are studies



indicating that mothers more likely to be unpredictable, intrusive and controlling, using more coercive feeding styles. The research goes further in noting that parents are less likely to respond affectionately or be flexible in their approach toward the child (Chatoor et al., 1998; Stein et al., 1994). Feeding disorders should therefore be considered within a relational context where the child and the parents' actions impact upon one another and treatments should be carried out accordingly. The following section goes further in discussing whether it is possible to find clear underlying causes for feeding disorders.

### 2.3.1. Organic versus Non-Organic Causes of Feeding Disorders

Whilst the aetiology of each child's feeding disorder may involve the interaction of a number of factors, the following section delves into whether feeding disorders can be understood as being derived from either a medical/developmental origin, a 'breakdown' within the family system or whether the development of feeding disorders has a more complex aetiology. Previous research has sub-categorised the onset of feeding disorders into: underlying medical factors, interpersonal aspects of feeding disorders (such as the parental relationship with the child) and behavioural and psychological factors pertaining to the child in isolation (Linscheid and Murphy, 1999).

More recent literature has acknowledged the complex interplay between medical, inter-personal and behavioural/psychological factors in the onset of paediatric feeding disorders (Chatoor et al., 2001; Piazza, 2008). Field et al (2003) in a hospital based study found in a group of 117 children displaying food refusal, all but one had co-morbid medical diagnoses, with the most frequent being gastro-oesophageal reflux, followed by a range of medical conditions such as heart conditions, neurological disorders, allergies and gut/digestive abnormalities.

The impact of underlying medical issues on feeding can be dramatic as the child is likely to associate feeding with significant distress and will therefore be more likely to avoid negative experiences (Hyman, 1994). Without proper management of medical problems, feeding disorders can arise and will have a

significant impact on the child and family's psychosocial wellbeing alongside increasing health concerns due to lack of nutritional intake. Gastro-intestinal problems or reduced oro-motor skills cannot always be fully managed by medical/physical intervention and therefore families often need further support to encourage positive experiences around feeding.

Food refusal appears to have a clear origin in cases where there are early or ongoing medical issues. However it can be exacerbated by parental interactions at mealtimes, relationship with the child or individual child characteristics. Such influences are notoriously hard to research as, owing to each of the factors impacting on one another; it is hard to determine which factor has the greatest impact on the feeding disorder.

Fisher and Silverman (2007) argue that caregivers are likely to become frustrated with their child whether the origin of the feeding disorder is biological or behavioural. However, it was not possible to find any research into whether parental perceptions of the origin of the feeding disorder impacts on how parents respond to their child at mealtimes, for example whether more punitive/coercive strategies are used if the parents believe the child is 'acting up' as opposed to having a medical difficulty. The following two sections explore the impact of developmental delay and Autism as potential causes of feeding difficulties and the possible overall impact of managing a child with multiple needs within family systems.

### 2.3.2. Developmental Delay and Feeding Disorders

There is a high incidence of feeding disorders in children with a developmental delay, with up to 80% of children displaying a feeding difficulty of varying degree (Rempel, Colwell, & Nelson, 1988; Sullivan et al., 2000). Although feeding difficulties are often present in children with developmental delays, they may not always be the main concern of the parent, as their child might present with a range of behavioural and developmental challenges that need to be attended to alongside their feeding (Gottmaker et al., 1990). However, in cases where feeding difficulties are present, parents may (as with typically developing children) experience increased stress at mealtimes and

spend disproportionate amounts of time trying to feed the child, which may lead to increased distress for the child (Lindberg et al, 1996). Schwarz (2003) asserts that distress in the child is likely to increase behavioural challenges and can be to the detriment of attending to the child's other developmental needs.

Having a child with developmental delays can elicit complex emotions in parents, for example they may be in a state of grieving for the child they had imagined and the reality of their child having developmental delays often means that their expectations of parenthood are not fulfilled in the way they had imagined (Fraley, 1990). There are studies highlighting that the increased stress of managing a child with multiple developmental needs can be disruptive to relationships within the family (Gath, 1973; Quine & Pahl, 1985). It can be hypothesised that if such disruptions occur, the feeding relationship might breakdown further, as parents might struggle to remain calm in their approach, possibly leading to heightened anxiety for the child around feeding times. Dunst et al (1990) noted that parents of children with developmental delay often feel isolated and unable to cope with the frequent challenges faced, this can lead to not obtaining support from services where they are available, possibly leading to further distress in the parents and child (Andrew & Sullivan, 2010).

High levels of depression are found in parents of children with learning disabilities (Veisson, 1999). Parental depression has been identified as an indicator for poor outcomes in interventions for children with learning difficulties and behavioural problems including feeding (Brinker et al., 1994). The presence of parental low mood can make mealtimes even more stressful for both parent and child (Sullivan et al., 2002).

### 2.3.3. Autism Spectrum Disorders and Feeding

There is a particularly high incidence of feeding difficulties in children with Autism Spectrum Disorders (ASD), with studies finding that between 46 and 75% display challenging feeding behaviours (Ledford & Gast, 2006). Such behaviours can include: food refusal, restricted diets comprising of less than

20 foods, leading to a compromised nutritional intake, and inflexibility regarding colour, texture and presentation of meals (Johnson et al., 2008; Twachtman-Reilly et al, 2008). Sensitivity to colour, texture and taste are common in children with ASD, with particular preferences extending beyond food. Children with ASD often display a range of difficulties, which are often considered the 'triad of impairment' (Wing & Potter, 2002), indicating that the child will display difficulties in three areas: social and emotional, language and communication and flexibility of thought. Emotional relationships can often be difficult for children with ASD to understand, sometimes leaving parents feeling bereft as they do not get the desired reciprocal responses from their child (Morgan, 1988).

A recent study by Rogers, Magill-Evans and Rempel (2012) highlighted the difficulties that mothers of children with ASD face when trying to feed their child; with an emphasis on how alone they feel in finding a means to ensure their children manage a balanced diet. One of the more poignant messages from this study was that clinical services were often unable to offer the support they needed in trying to overcome any feeding disturbance. Field et al (2003) and Lewinsohn et al (2005) advocate for a full medical investigation where the cause of the feeding disturbance is unclear. It appears that by treating feeding disorders differently where an ASD is present (owing to clinicians feeling unable to support change) can lead to serious health concerns and children possibly being left in physical distress (Rogers, Magill-Evans and Rempel, 2012). Twachtman-Reilly et al (2008) found that having a diagnosis of ASD often precluded families from being referred to specialist feeding services.

Evans-Morris and Dunn-Klein (2000) stated that children with ASD and feeding difficulties and their families need a comprehensive assessment by a multi-disciplinary team in order to understand feeding behaviours in context. Without an in-depth understanding of the cause of the feeding difficulty, the family and child are likely to be left in a stressful situation, where feeding may worsen (Rogers, Magill-Evans & Rempel, 2012).

Whether the feeding difficulty is biological or relational in origin, much of the emphasis of the development and maintenance of feeding disorders has focussed on the relationship between mother and child, where the mother is considered the primary caregiver. The following sections explore how relationships and attachment can affect feeding, moving on to exploring the wider system that includes fathers as well as mothers.

#### 2.3.4. The Mother-Child Relationship

The relationship between mother and child has historically been the focus of both research and treatment of feeding and eating disorders, where it is understood that this pairing is the key to both the development of the problem and, by implication, the treatment (Chatoor, 1997; Chatoor et al., 1998). There is a high incidence of mental health difficulties amongst mothers of children with feeding disorders, mostly anxiety and depression (Coulthard & Harris, 2003; Lindberg et al., 1996) and it is unclear whether they are causal or subsequent to the problem. Depressed mothers may be less sensitive and responsive to the needs of the child and may be somewhat unpredictable and unavailable (Cummings & Davies, 1994). These characteristics are often associated with the onset of childhood feeding problems (Lindberg et al., 1996).

Mothers with a history of eating disorders have also been found to have a higher incidence of infants and children with feeding difficulties (Micali, Simanoff & Treasure, 2009), associated with a controlling or disorganized style during mealtimes. There is evidence that mothers who suffer, or have previously suffered from an eating disorder are more likely to have a child with a feeding disorder (Whelan and Cooper, 2000), a similar figure to mothers who have psychiatric diagnoses (Micali et al., 2009).

Earlier research on the cause of feeding problems asserts that the difficulties stem from the child trying to achieve separation and individuation from the mother (Chatoor, 1989). These ideas stem from Bowlby's Attachment Theory (1988), where a securely attached mother and child are able to read one another's cues and the child is able to develop its own preferences, safe in

the knowledge that its mother will respond to changing needs in a positive and sensitive manner (Schoore, 1994).

#### 2.3.5. Attachment and Early Feeding Relationships

Attachment Theory (Bowlby, 1969) notes that from the earliest moments in life, mothers and babies develop a reciprocal relationship, through which they learn to understand one another's cues, however this process is complex and not always achieved. One of the earliest acts is that of feeding, which forms an important platform for parent-infant attachment to occur (Hagekull & Dahl, 1987). The act of feeding not only provides nourishment for the infant; it enables physical closeness, comfort and security (Pridham et al., 1982).

Feeding is a complex act where the mother or father has to learn to understand their child's cues and feed at the appropriate times. Through this process, the child learns to understand their internal sensations (Chatoor, 1989; Greenspan & Porges, 1984). At the start of the parent-child relationship, the child's cries are often indistinguishable and the primary caregiver does not always give the appropriate response. Whilst this is common in the earliest stages of life, over time the 'securely attached' mother and baby will develop a language of their own, through which the mother will give the desired responses the majority of the time (Bowlby, 1969; Jacobvitz & Sroufe, 1989) and the child will in turn offer the mother the closeness she desires, for example offering eye contact and being settled in the mother's arms.

There are many physical processes that have to occur for feeding to be successful, for example the child being able to latch and suck on the breast or bottle. The occurrence of medical conditions such as reflux or developmental delay can also impact on feeding. Early feeding can very quickly turn from being a pleasurable act between parent and child, to a highly stressful event (Chatoor & Egan, 1983). Feeding can become the centre of the relationship, which can begin to break down, as neither parent nor child get the responses they desire. Studies indicate that there is increased parental stress in families where a child has a feeding disorder (Didehbani et al., 2011) and the child picks up on the stress and anxiety displayed by the parent, causing the child's

behaviour to become more difficult at feeding times. The parent can rapidly become the stimulus that indicates feeding and the child moves to reject the parental advances during feeding (Brehm, 2004). Whilst it appears that the overarching sense is that the mother-child relationship is at the core of the feeding relationship as they are more often the primary attachment figure, fathers are increasingly involved in childcare and as such can be considered to play an important role in the general development of their children. And as such should be considered as part of the relational model of feeding.

#### 2.3.6. Moving Toward a Relational/Triadic Model of Feeding

Recent literature argues for feeding disorders to be re-conceptualized as a relational disorder (Davies et al, 2006), moving away from seeing the disorder as individual to the child to being a difficulty that exists between the child and the wider system (Manikam & Perman, 2000). Satter (2005) asserts that the parent and child come to the feeding relationship with their own pre-disposing factors, whether environmental or physical. The parent needs to be attuned to the child's hunger and satiation cues, along with understanding their developmental level (for example offering the correct textures and tastes).

Within this framework it is considered that there should be a 'goodness of fit' between the parent and child, as there are a number of complex tasks that must be established for successful feeding to occur (Satter, 1990). As the child develops the parent must allow for the child to become increasingly autonomous, whilst ensuring they receive adequate nutrition for growth. This task can cause anxiety in the parents; as the child remains in control of whether they will eat and how much they will take (Satter, 1990). Satter (1990) goes further in asserting that the child may not fulfil the parents' expectation of what is 'enough', perhaps resulting in the parent becoming controlling about how much the child 'should' be eating and cause mealtimes to become a negative experience for both parties. In a healthy feeding relationship the parent will adapt positively to changing developmental needs and preferences of the child, whilst ensuring they receive an adequate nutritional intake.

From foetus to early childhood, the child cannot exist in isolation, with the parents being the only means to the child receiving care and nutrition. If there is a breakdown somewhere within the parent-child partnership, whether it be a physical/medical process within the child causing pain when feeding, or whether the parent misreads hunger or satiation cues, the only means by which to begin treating the problem is to ensure that the parent and child are able to enter into a reciprocal relationship where the parent is able to learn how to meet the child's needs and the child can trust that feeding is a safe and contained process (Davies et al., 2006; Satter, 2005). It can be hypothesised that even if the reasons for feeding problems are based on medical difficulties, it is likely that the parent-child relationship will be impacted both during and outside of feeding. It is important that this relationship is considered as extending beyond mother and child, as in today's society fathers have an ever-increasing role within the family and can in some cases be the primary caregiver. The following section focuses on the role fathers can play in feeding.

#### 2.3.7. Fathers and Feeding

In the few recent studies that have focussed on paternal factors, there have been findings to show that fathers play a role in the onset of their child's feeding disorder and are significantly impacted by it. Piepenstock (2010) found when looking at a group of fathers within a clinical population of children with feeding disorders as compared to controls, the clinical fathers were significantly more stressed. However it was unclear whether the stress was directly related to the feeding itself, or whether it was the impact of the feeding disorder on familial relationships that was the cause.

Atztaba-Poria (2012) recently looked at parent-child interactions during play and mealtimes in clinical and control groups and coded the interactions into positive and negative styles. They found that both mothers and fathers displayed higher levels of negative interactions during both scenarios as compared to controls. Fathers have also been found to have higher levels of depression with a child with a feeding disorder than controls. The depression may reduce paternal sensitivity and can in turn mediate maternal sensitivity



(Gueron-Sela et al., 2011).

Studies from within the eating disorder literature illuminate the paternal influence in their onset and management. Fitzgerald and Lane (2000) assert that it is not the relationship with the mother alone that creates a rigid and homeostatic system in which the child/adolescent with an eating disorder struggles to gain autonomy and individuate (often considered a significant cause of eating disorders – Minuchin, 1978; McCarthy, 1998). The father also plays a role in denying the child autonomy, whether it is from the periphery or as a figure-head within the family (Fernandez-Cossgrave, 2013). Newton et al (2006) state that positive involvement from fathers is important in facilitating their daughter's separation and development and should therefore be included in eating disorder treatment.

The impact of paternal influence on mothers can be seen from the earliest moments, where paternal preference for the mother to breastfeed was a mediating factor in how mothers chose to feed the child (Scott, Binns & Aroni, 1997). Fathers are also cited as important in the general development of children, for example children with actively engaged fathers, display higher cognitive functioning, greater empathy and are better able to cope with social demands (Maine, 2004).

#### **2.4. The Impact of Feeding Disorders on Parental Mental Health**

Whilst it is not possible in many cases to establish whether parental mental difficulties are a precursor to or result of feeding problems in the child, recent literature has focussed on the impact on parental mental health within a feeding disorder framework. When conducting a literature search on feeding disorders and parental mental health, frequently cited mental health concerns were that of; stress, coping, anxiety, depression and loneliness/social isolation. These were anecdotally also considered to be frequently mentioned concerns within the Feeding Disorder Service at GOSH. These were therefore the focus of the study and are considered in more detail below. Whilst a further concern raised was that of parental relationships in feeding disorders, a recent study by Piepenstock (2010) had focussed on the parental

relationship and it therefore seemed more useful to look at other areas of concern rather than to replicate a recent study from within the same service.

#### 2.4.1. Parental Stress and Coping

In the case of childhood chronic illness it has been found that parents experience increased levels of stress (Didehbani et al., 2011; Auslander, Netzer & Arad, 2003). Similarly with feeding disorders, ensuring the child receives adequate nutrition becomes a daily battle for parents (Auslander et al., 2003). Graves and Ware (1990) found that parents of children with feeding disorders often struggle with the extra demands placed on them, such as monitoring daily intake or managing tube feeding, which leads to higher levels of stress than in parents of healthy children (Franklin & Rodger, 2003; Pederson et al., 2004). It has been found that the greater the needs of the child, the less equipped the parent feels to manage them and the higher the levels of stress in the parent (Brehm, 2004).

Owing to feeding being a relational process, parental stress and distress can be considered likely to impact on the child, particularly during feeding itself, as parent-child interactions have been found to be pivotal in the initial presentation and maintenance of feeding difficulties (Riordan et al., 1984).

In order to manage the increased demands of having a child with feeding difficulties, parents often have to develop coping strategies (Brehm, 2004). Whilst some parents adopt adaptive coping styles to manage their stress and frustration at mealtimes, many parents develop maladaptive coping mechanisms such as 'force-feeding' (Raina et al., 2004).

There are limited studies exploring parent-child interactions during mealtimes (Williams, Hendy & Knecht, 2008), however those that have taken place find that parents of children with feeding disorders use more aversive comments and instructions than parents of healthy children (Palmer and Horn, 1978; Sanders et al., 1993). This, in turn, appears to lead to greater food refusal and disruptive behaviour during mealtimes than in children without feeding difficulties (Sanders et al., 1993). The parent and child can become bound up

in an endless cycle of negative and intrusive behaviours by the parent and increased food refusal by the child (Brehm, 2004). Bearing this in mind, it is imperative that the parent learns to regulate their stress and negative responses during mealtimes, in order to support the child to manage mealtimes in a more positive manner (Didehbani et al., 2011).

Palmer and Horn (1978) noted that 21% of the feeding difficulties presenting in their feeding program were related to poor mealtime management. It is therefore important that therapeutic programmes for children with feeding disorders actively encourage working with parents alongside the work with children, as reducing parental stress and promoting adaptive coping styles, is likely to have a significant impact on the child's feeding behaviours.

#### 2.4.2. Anxiety in Parents of Children with Feeding Disorders

Having a child with feeding difficulties can be a cause of great anxiety in parents (Chatoor et al., 1997), particularly for those who are more vulnerable. Chatoor et al (1997) states that mothers can begin to feel insecure about their parenting skills, thereby becoming forceful in their feeding style in order to ensure that their child receives nutrients. Whilst it is clear that the child must eat, Chatoor et al (1997) argue that the parental anxiety can stand in the way of problem solving and the parent and child enter into a negative cycle of force feeding and refusal, leaving the child in a state of distress and the parent in a heightened state of anxiety.

Gueron-Sela et al (2011) found that the greater the maternal anxiety in children with feeding disorders, the higher the incidence of negative mother-child interactions. It can be hypothesised that with the experience of feeding being at least three times a day, mothers may struggle to enter into positive interactions with the child as the intervals between meals does not leave enough time for the heightened state of arousal to reduce. Gueron-Sela et al (2011) argue that maternal anxiety must be considered a factor in the treatment of children with feeding disorders and that clinicians need to help mothers to move away from the constant surveillance of their child's meals and weight gain, toward developing gentle, positive and structured mealtimes.

Within this framework the mother also needs a space to 'offload' and discuss their anxieties, which clinicians should be able to offer as part of the treatment.

Whilst this study and many others within the feeding disorder literature focus on mothers, fathers are evermore involved with their children's upbringing and it can be hypothesised that they are unlikely to be devoid of anxiety when it comes to their child's feeding disorder. As previous studies have highlighted, fathers of children with feeding disorders are significantly more stressed than those in a non-clinical cohort (Piepenstock, 2010), it is important to consider that the stress may in part be derived from a heightened state of anxiety in direct relation to feeding or a response to maternal anxiety and strained relationships within the family.

#### 2.4.3. Parental Depression and Loneliness in the Context of Childhood Feeding Disorders

Depression is a psychiatric disorder that affects a significant proportion of the population. Studies have found that depression often occurs in mothers and fathers of young children (Kane & Garber, 2004) and there is an increased risk in parents of children who present with a disability or illness (including feeding disorders) due the increased level of stress associated with care (Chatoor, 2000; Veisson, 1999). Whilst there is a wealth of research detailing maternal depression in feeding disorders, only one study was found that focussed on paternal depression.

Gueron-Sela et al (2011) found there to be an elevated level of depressive symptoms in fathers of children with feeding disorders as compared to controls. Within the research cohort it was noted that the incidence of depression had a significant impact on the father-child relationship, reducing their sensitivity toward their child. As children with feeding disorders need higher levels of patience and gentle prompting to feed, it is likely that if fathers' depression is left untreated there will also be a negative impact on the child's feeding. A further outcome of the study was that paternal depression also impacted on the mother-child relationship, reducing maternal sensitivity

toward the child. This indicated that without addressing paternal mental health in treatment, the feeding triad is likely to be impaired. Fathers should therefore be included in feeding disorder treatment alongside mothers.

A recent study by Golik et al (2013) highlighted that there were significantly higher levels of depressive maternal cognitions in mothers of children with feeding disorders as compared to controls. However the study also found that maternal depressive feelings and childhood feeding disorders are bi-directional, and therefore it is not possible to distinguish whether maternal depression is causal of feeding disorders or vice versa. Hellin and Waller (1992) found that maternal mood greatly influences how they interpret their child's feeding practices; for example, mothers who displayed post-partum low mood/depression experienced their children as fussier and more demanding, often moving on to bottle feeding faster than those without depressive symptoms. Farrow and Blisset (2006) also found that maternal reporting of feeding difficulties in their children was highly correlated with higher levels of emotional deprivation, and less desire to sacrifice their own needs in favour of their child during pregnancy.

Depression in parents, similarly to anxiety is likely to impact how they experience their child during mealtimes. For example, they may experience prolonged and difficult feeding practices as more stressful than a parent without low mood and may in turn respond negatively towards the child, reinforcing difficult behaviour (Feldman et al., 2004; Golik et al., 2013). Ammaniti et al (2009) noted that depressed mothers offered less physical interaction with their child during feeding, and often displayed sadness and anxiety during feeds. Owing to the mother's depressed state, she may also struggle to recognise and respond to her child's expression of emotion during feeding, for example continuing to feed when the child is clearly in distress (Ammanati et al., 2009). It is with this in mind that parental mental health must be considered as important when offering treatment for children with feeding disorders.

Feeding disorder research has shown that mothers of children with feeding

difficulties often have a poor social network, with limited support from their spouse and extended family (Sanders et al., 1993). Farrow and Blissett (2006) found that in a sample of 99 mothers of children with feeding disorders the experience of significant loneliness and poor self-esteem was extremely common. These feelings coupled with the stressful impact of the feeding disorder on the family, may cause a further withdrawal from society, perhaps leading to a general sense of isolation, which may impact on other areas of parental mental health and ability to cope with the impact of their child's feeding disorder. There was no literature found discussing whether fathers experienced increased isolation if their child had a feeding disorder.

## **2.5. Treatment for Feeding Disorders/Avoidant Restrictive Food Intake Disorder**

The following sections detail the current models used within the treatment of feeding disorders and explores the idea of parent group intervention and its potential usefulness in the treatment of feeding disorders.

### **2.5.1. Moving Toward Systemic Intervention**

Until recently, feeding has been understood as a process that occurs between mother and child (Atztaba-Poria et al., 2010). It is helpful to understand the feeding problem from a wider systemic viewpoint as this removes the implication of an individual being at fault and sees each member of the system offering a potential solution (Parry & Doan, 1994). By widening the system, there is an acknowledgment that the feeding difficulty does not only exist between mother and child, but that the father can play a pivotal role in not only feeding management but in ensuring the relationship between mother and child does not break down (Atztaba-Poria et al., 2010). From the earliest moments of life, fathers can impact on the feeding relationship, for example fathers approving of and encouraging breast-feeding leads to a higher incidence of mothers breastfeeding their infants (Littman et al., 1994).

Whilst on the whole it seems that maternal involvement in the home is higher than fathers, there has been a significant increase in fathers playing a greater part in their children's upbringing and development (Bader & Phillips, 1999;

Lamb, 2004). Fathers' involvement does not necessarily influence child development over quality of mothering (Parke & Buriel, 1998), but there is evidence to show that paternal involvement can significantly increase maternal sensitivity toward the child (Belsky et al., 1989; Feldman et al., 1997; Levy-Shiff & Israelashvili, 1988). Co-parenting is considered important in children's development (Minuchin, 1985); a functional parenting alliance supports communication and is an immediate support system that reduces parental stress (Weissman & Cohen, 1985).

Whilst current treatments aim to include fathers in assessment, and where possible in ongoing intervention, there are not currently any specific group interventions that are tailored to fathers as well as mothers. The current treatment for feeding disorders is detailed below.

#### 2.5.2. Current Treatment of Feeding Disorders in Early Childhood

Due to the recent re-conceptualisation of feeding disorders as a product of bio-behavioural influences (Fischer & Silverman, 2007) and arguments by Satter (1990) and Bryant-Waugh & Piepenstock (2010) that feeding disorders should be considered relational, current treatment programs aim to encapsulate these ideas. Fischer and Silverman (2007) offer a comprehensive overview of the assessment and treatment program that is widely used within specialist feeding disorder clinics. The treatment approach at Great Ormond Street Hospital (GOSH) where the study was carried out uses a similar model.

Prior to the commencement of treatment, a multi-disciplinary team carry out a comprehensive assessment. This covers the medical, physiological, psychological (both individual and systemic) and behavioural aspects of the child's feeding disorder. The child is often observed during a mealtime and parents are asked to give a full history of the child's difficulties plus a family history. It is hoped that this will enable the clinicians to formulate an idea of the origins and maintaining factors of why both the feeding and feeding relationship have broken down. The feeding disorder team at GOSH uses the

Behavioural Paediatric Feeding Assessment Scale (Crist et al., 1994) to help determine the severity of the problems presented.

The outline by Fisher and Silverman (2007) places an emphasis on the behavioural treatment of feeding disorders, with clinicians such as Clinical Psychologists and Specialist Nurses focussing on parental interaction with the child during meals, encouraging a more positive and less stressful environment in which to promote feeding. There is also a focus on feeding skills by speech and language and occupational therapists to ensure that the child is able to manage different tastes/textures and has all the physical skills needed to feed. The children are encouraged to face new food through play and are slowly introduced to new and greater amounts of food. Anecdotally, feeding clinics are more often only attended by mother and child, even though family therapy is often offered. The systemic element is pivotal to treatment, as the child's feeding disorder does not exist in isolation. There is a move towards encouraging greater paternal involvement in the treatment of feeding disorders as fathers are increasingly seen to play a significant role in the family system, in both maintaining the disorder and offering tools to support recovery.

#### 2.5.3. Parent Groups for Children with Feeding/Eating Disorders

Current interventions for treating feeding disorders in early childhood are largely individual or to some extent family based, occurring within clinical settings and focus on behavioural/psychological issues in the child and parent-child interactions (Haywood & McCann, 2009). Although the studies focussing on group work for parents (usually mothers) are limited, there appear to be significant improvements in those that have been trialled (Douglas & Harris, 2001; Fraser et al., 2004; Haywood & McCann, 2009). A recent study by Bryant-Waugh et al (2007), describes the development of a parenting skills and support group for mothers with eating disorders (who often have problems feeding their children). The study piloted an eight-session group to promote positive parenting practices and was found to increase confidence in parenting ability and reduce levels of depression (Bryant-Waugh et al., 2007). This study was found to be both feasible and



valued by parents. Jones and Bryant-Waugh (2012) piloted a group for mothers of children with feeding difficulties, the group aimed to address maternal psychopathology, parental stress, and the impact on the feeding relationship. Whilst there was no significant change in psychopathology or stress, there was nevertheless some improvement in how the mothers felt and they reported finding the group highly beneficial, as they felt supported and understood. It was noted that the sense of isolation that the mothers had initially felt had reduced, as they were able to share their experiences with those in a similar position. It was also of importance within this study that the mothers and clinicians shared similar ethnic and social backgrounds as this added to the perceived sense of support and understanding.

Haywood and McCann (2009) piloted a 'Fun with Food' group intervention for parents and children to promote healthier feeding practices amongst 'hard to reach' families in East London. It is notable that the cohort presented with non-clinical feeding difficulties, with the aim of offering useful strategies to prevent children needing to access services later. The intervention included four sessions a week apart, including psycho-education, group discussions, food play/preparation and homework setting. A follow-up session was offered a month later. Outcomes were measured using a shortened BPFAS (Crist et al., 1994). Outcomes relating to parental worry were reduced and remained so at follow-up, with feedback stating that the ability to discuss issues with other families in a similar situation felt both reassuring and supportive. The scores relating to children's feeding also improved, however these were not all maintained at the time of follow-up. Whilst the main aim of this treatment was not necessarily to provide psychological support to parents, it appears that the group element of this study offered emotional and social support. It is of note that it was largely mothers who attended these groups with their children and fathers were not specifically targeted to attend.

A further group intervention trialled by Fraser et al (2004) used a one off psycho-education model to offer support in developing positive interactions at mealtimes and move away from coercion and punishment. Outcomes included parents noting a significant decrease in 'problem eating', however it

was not clear whether a long-term outcome was achieved. However this study also appears to indicate that group interventions can be effective, and it can be hypothesised that part of the effect is due to the group dynamic and support from other families in similar situations.

Whilst the parent groups have reportedly been effective, they do not place an emphasis on involvement of fathers. In fact it was not possible to find a group within the feeding disorders literature that has specifically included fathers, even though more recent systemic interventions invite fathers to be a part of the intervention. Owing to the previously stated benefits of fathers becoming involved in the parenting, it seems that this is an area of research that should be targeted.

As noted with the educational group piloted for mothers of children with feeding disorders (Jones & Bryant-Waugh, 2012), 'similarity' of other group members was viewed as positive. It was not possible to find any piloted or established therapeutic groups for parents of feeding disordered children that looked at the parental understanding of the origin of the child's feeding disorder as a means to tailoring the group intervention. Within the current study, the areas of interest are severity of feeding disorder; presence of developmental delay; underlying medical problems and behavioural/psychological influences (with an overarching emphasis on inter-personal relationships). It is possible that these aspects of each child's feeding disorder may be of importance when deciding on the type of support needed by the family. In many cases there may be a distinct overlap in some of these areas, for example, parents of children with Autism or severe developmental delay and feeding disorders. It can be hypothesised that families where the child has multiple difficulties alongside feeding have more stressors than stressors than parents of a child where for example reflux is the underlying cause, as the families may need to attend to varying needs associated with ASD or developmental delay, such as poor sleep or behavioural challenges (Johnson et al., 2009). The interventions can thereby be tailored to each group of parents enabling them to feel less isolated.

## **2.6. Rationale for the Current Study**

Recent literature indicates that feeding problems are best managed within a systemic context (Douglas & Harris, 2001; Fraser et al., 2004; Haywood & McCann, 2009). Currently, the main body of research in this area focuses on the mother-child relationship and the complexity of the interactions that occur around the feeding difficulty (Chatoor et al, 1998). This relationship is pivotal in the feeding relationship and must be addressed in the treatment of feeding problems. However it must be acknowledged that the mother-child relationship does not exist in isolation. The role of the father has received little attention in the treatment of feeding problems both in the literature and clinically. It has been established that fathers play an important role in the healthy development of the child and in the enhancement of the mother-child relationship (Feldman et al., 1997), both of which need to be attended to when treating children with feeding problems.

No evidence-based group interventions could be found that involved both parents in the treatment of feeding disorders. A recent study by Piepenstock (2010) indicates that fathers of children with feeding problems display higher levels of stress than those where feeding problems are not present. This is likely to impact on all the relationships within the family system, perhaps leading the father to reduce his involvement with members of the family or feeling less able to support the treatment of the child. There is research to suggest that paternal eating behaviour also plays a role in the development of childhood feeding and eating practices (Johannsen et al., 2006) and that lower paternal involvement is more common in families where a child has a feeding disorder compared to control groups (Atzaba-Poria et al., 2010). It is therefore indicative that fathers should be included in the treatment of feeding problems, as they have a potentially valuable role to play.

Whilst there are relatively few skills and support interventions for parents of children with feeding problems that have been documented, those that have been evaluated have been well received. However, as there has not been a group where both parents are invited to participate, there is little indication as

to what topics would be useful to both mothers and fathers. The emergent study would be an initial stage in the development of a novel intervention for parents, and would be used as a way of identifying the differences in experience between parents on a number of key variables that are relevant to feeding (e.g. anxiety, depression, stress, social isolation and coping). This would be useful in deciding the content of the support group, as more prevalent issues would be given greater weighting. These five variables were identified following discussions with clinicians at the Feeding Disorder Service at GOSH as being frequently identified issues with presenting families and was decided upon following a literature search that reflected the practice-based evidence of the service. However it is of note that the majority of the literature focussed on the impact on mothers and fathers were largely excluded.

The investigation might also identify whether other variables - such as the age of the child, presence of global developmental delay and whether the feeding problem was medical in origin - affect parents differently, thus indicating the need for separate/tailored support groups. The age range of 0-8years was decided upon as this is in line with the criteria for the Feeding Disorder Team at GOSH and is the age range that the Behavioural Paediatric Feeding Assessment Scale (Crist et al, 1994) is targeted at, which is the assessment tool used within the service.

Owing to the nature of this study comparing scores between mothers and fathers on a range of variables, only families where both mothers and fathers were involved in parenting, were invited to take part, therefore no solo-parents or single sex parent couples were approached.

The longer-term aim of this study is to target fathers to take part in treatment alongside mothers, for the content of interventions to be considered in light of the findings of this study and to disseminate findings to other services to inform the content of interventions.

### 2.6.1. Research Aims

The general aim of the study is to add to the current evidence base on the types of issues that might usefully be addressed in interventions for mothers and fathers/primary carers of children with feeding problems and identify whether parents of children with different presentations might have different needs and priorities, suggesting the usefulness of tailored interventions. The specific aims were:

1. To gather information regarding a number of parent variables previously demonstrated as being associated with having a child with a feeding disorder to inform the development of novel interventions aimed at both parents; that is, to clarify and prioritise potentially useful areas to address in novel group/couple interventions for mothers and fathers of children with feeding problems, in particular to ensure that fathers' needs are attended to as well as mothers'.
2. To investigate differences between male and female parents on a number of key variables demonstrated to be associated with having a child with a feeding disorder or of relevance to feeding, in particular; anxiety, depression, stress, social isolation and coping style, in order to inform content and focus of novel parent interventions, to promote mutual parental understanding and support.
3. To explore whether the focus of parent interventions may need to differ according to characteristics of the child's presentation, for example: age, broad type of feeding problem (medical/non-medical; ASD/no ASD/ASD features; tube fed/ no tube), and severity of feeding disorder.

### **3. METHODOLOGY**

#### **3.1. Design**

This study has a quantitative, questionnaire based, independent groups design. A quantitative design was used as it enabled the researcher to gather information on pre-identified variables that have been found to have an impact on parents of children with feeding difficulties. By using a questionnaire-based design it enabled the researcher to compare mothers and fathers on the five chosen variables, thereby helping to establish how mothers and fathers might be differently impacted by their child's feeding difficulty. By using a quantitative design, it enabled the use of precise measurements of the constructs being tested and allowed for their comparison (Barker, Pitstrang & Elliot, 2002). By employing the use of questionnaires it ensured that the questions asked were reliable at testing the constructs being looked at in the study and which had been used in previous research.

The current study involved asking mothers and fathers of children who were referred and offered treatment at a tier 4 specialist Feeding and Eating Disorder Service from February 2012 for a 3 month period. This was to ensure that some families had not received a disproportionate amount of treatment compared to others. Owing to the study being exploratory, rather than hypothesis testing, and specific to this clinical cohort, a control group was not indicated. The researcher considered adding a qualitative element in the form of a focus group in order to further explore the impact of having a child with a feeding disorder on both parents, however owing to the distance travelled by most patients (as the service is offered nationally) it did not seem feasible to hold a focus group with a range of families who were not being offered treatment either prior to or following the focus group. Couples interviews were considered, however it was thought to preferable to develop the narrative in a group setting rather than individually.

### 3.1.1. Materials

Based on a review of the existing literature, five factors were identified that are either associated with being a parent of a child with a feeding disorder or have been shown to be relevant to feeding. Importantly, all are also demonstrated as being amenable to change through targeted intervention. These include; stress, depression, anxiety, social isolation/loneliness and avoidant coping style. Following the identification of these factors, a set of questionnaires was identified that map on to these factors: Parent-Stress Index-36 (Abidin, 1995), Beck Depression Inventory (Beck, 1996), Beck Anxiety Inventory (Beck, 1990), UCLA Loneliness Scale (Russell, 1996) and the Brief COPE (Carver, 1997) (Appendix 4). The reason for the choice of each measure is described in further detail below. The BPFAS (Crist et al, 1994) and the demographic questionnaire are also described (Appendix 5 & 6). Whilst issues pertaining to the parental relationship have also been identified as being pertinent to feeding disorders, a recent study within the service focussed on maternal gate-keeping, father-involvement and parenting alliance. It therefore seemed more useful to focus on issues that were not recently explored and have been identified as potentially useful to address already.

#### *3.1.1.1 Parenting stress*

Parenting stress has previously been defined as the negative psychological response to the difficulties of parenting (Deater-Deckard, 1998). Whilst parenting can be stressful in general, there is often increased distress when there are further issues such as developmental delay or an ill child. Owing to the daily struggle of having a child with a feeding disorder, it seemed important to measure how parents react in the face of ongoing feeding difficulties.

There are a range of questionnaires available to assess parenting stress including the Parenting Stress Index – Short Form (Abidin, 1995), the Pediatric Inventory for Parents (PIP) (Rodrigue, Geffken & Streisand, 1999) and the Parental Stress Scale (PSS) (Berry & Jones, 1995). The latter two questionnaires were considered for use, however the PIP was developed for

children with critical illness and/or physical disability and whilst for some of the children in the study this might have been applicable it was not felt to encompass the presentation of the children attending the feeding disorder service as a whole. The PSS is only an 18-item questionnaire and does not contain items that pertain to the perceived difficulty of the child; it was therefore felt it did not offer enough information. The widely used Parenting Stress Index – Short Form (PSI-SF) was chosen for this study. The reasons for this choice are stated below.

The PSI-SF (Abidin, 1995) is a self-report measure that is used to both assess and analyse potentially dysfunctional interactions within the parent-child relationship. The 36-item measure was used as it is time efficient. It is derived from the original full-length version of the PSI consisting of 101 items (Abidin, 1983). It was felt that the direct and comprehensible language used by the PSI-SF (Abidin, 1995) lent itself well to the current study and the items related to parents with children aged between 1 month and 12 years of age, which covered the target age range of the children in this study.

The self-report measure provides information on; parental distress, dysfunctional interaction in the parent-child system and a score of the level of difficulty in how parents view caring for their child. The measure also yields a total stress score, giving an overall picture of the stress experienced within the parent-child system.

The PSI-SF is a widely used measure in both research and clinical settings (Reitman et al., 2002). It has been used in approximately 200 research studies between 1995 and 2010 (Abidin, n.d.) and has high internal consistency alpha coefficients, reported to be between 0.80 and 0.91 (considered to be good to excellent internal validity). Across the space of a year the test-retest reliability has been reported to be between 0.68 and 0.85 (Haskett et al., 2006). The PSI-SF also has good construct validity, as the questionnaire scores correlate well with observed parent-child interactions, parental understanding of their child's behaviour and measures of psychopathology within the parent (Haskett et al., 2006).



### *3.1.1.2 Depression*

Depression is a psychiatric diagnosis with both emotional and physiological aspects, including loss of pleasure, poor self-esteem, loss of appetite and disrupted sleep patterns (APA, 2000). It is possible to experience depressive symptoms without reaching clinical diagnosis.

There are many measures of depression. Those considered for use in this study were included the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), the Hamilton Depression Rating Scale (HDRS) (Williams, 1988) and the Beck Depression Inventory (BDI) (Beck, 1996). Whilst both the HADS and HDRS are widely used, the HADS is mainly used when there are physical health issues. The HDRS needs to be administered by a clinician and was therefore not useful for this study, as self-report measures were preferred.

The BDI-II (Beck, 1996) was chosen as the self-report measure for symptoms of depression in mothers and father of children with feeding disorders. It is currently the most widely used tool to measure the severity of depression within an adult clinical population and when helping to detect depression within the general adult population (Beck et al., 1996). For the purposes of this study (using a sample of non-clinical parents) the BDI-II was not used as a diagnostic tool as it cannot be used as such without clinical assessment (Beck et al., 1996). The measure comprises 21 items relating to the emotional, cognitive and physiological symptoms of depression (Appendix 4). Each question can be answered by circling a score between 0 and 3, where the higher the score the greater the severity of the symptom. The individual is asked to consider how they have felt over the previous two weeks, which was in line with the DSM-IV-TR diagnostic criteria for depressive disorders. Total scores range from 0-63, with scores over 19 being the clinical threshold for depression.

The psychometric properties of the BDI-II were validated by Beck et al (1996) on two cohorts: 500 adults attending psychiatric outpatient departments and 120 university students studying psychology. Beck et al (1996) found the BDI-

It to have high internal validity within both clinical and non-clinical populations, with alpha coefficients of 0.92 and 0.93 respectively. The test-retest reliability over a week gave a coefficient alpha of 0.93. Alpha coefficients above 0.90 are considered to have excellent internal validity. This tool is therefore considered to be the most successful self-report tool both in assessing the presence of depressive symptoms and their severity.

### *3.1.1.3 Anxiety*

Anxiety is defined as an emotional experience that is characterized by both cognitive and physical aspects, such as worry, tension and an increase in blood pressure, which can range from day-to-day worries to anxiety disorders where the symptoms intrude upon normal functioning (APA, 2013).

The State-Trait Anxiety Inventory (STAI) (Spielberger et al., 1983), The Hospital Anxiety and Depression Scale – Anxiety (HADS-A) (Zigmond and Snaith, 1983) and the Beck Anxiety Inventory (BAI) (Beck, 1990) were all considered for use in this study owing to their well-founded psychometric properties and their usefulness in detecting generalised anxiety (Julian, 2011). A recent review by Julian (2011) noted that the limitations to the STAI were that it has poor validity when differentiating between depression and anxiety and is meant for use over prolonged time periods and therefore may not be as useful as other measures when looking at a more recent time period. The review also noted that the HADS-A has good validity for detecting generalized anxiety however it is meant for use with medical populations and would therefore not be representative of the population in the current study.

The BAI (Beck, 1990) was chosen as a measure of the level of anxiety in the parents recruited within this study due to the measure being designed to discriminate between the symptoms of anxiety and depression. Even though it does not take into account milder symptoms of anxiety such as worry and focuses primarily on somatic symptoms (Julian, 2011), it was believed to be a suitable and comprehensible measure for this study.

The BAI is a 21 item self-report questionnaire that takes a short time to

complete; the questions require an answer between 0 and 3 depending on the severity of the symptoms experienced. The questions are written in a simple and comprehensible manner and the tool is widely used as a measure of anxiety in research and with clinical populations. The questions are designed to capture both the cognitive and somatic symptoms of anxiety, with scores from 16-25 being considered as moderate anxiety and scores above 25 as severe. There appears to be a higher level of accuracy when used within clinical populations (deAyala, Vonderharr-Carlson & Kim, 2005), however it is still considered to be a reliable tool.

The BAI has high internal validity, with alphas reaching 0.94 and test re-test reliability of between 0.67 and 0.75 (Beck et al., 1990; Fydrich, Dowdall & Chambless, 1992), with the retest period ranging between 7 to 11 days (higher alpha reported with a seven day interval). The BAI is considered to be a valid and reliable measure of anxiety. There is often a high level of overlap between scores on depression and anxiety scales, however the BAI is considered less tainted by depressive symptoms than other measures (Clark, Steer & Beck, 1994).

In this study the BAI was not used as a diagnostic tool, but rather a measure of the presence and severity of symptoms of anxiety.

#### *3.1.1.4 Loneliness*

Loneliness has previously been defined as the how much meaningful social and emotional interaction and support received, as compared to the reality (Peplau & Perlman, 1982; Fees, Martin & Poon, 1999). As with the other constructs being explored, there are a wide range of experiences of loneliness and isolation, with the milder end being short-lived and the more extreme feelings of loneliness being an ongoing aspect of daily life.

The loneliness measures considered for use within this study were the de Jong-Gierveld Loneliness Scale (de Jong-Gierveld, 1987), the Social and Emotional Loneliness Scale for Adults (SELSA) (DiTomasso & Spinner, 1997) and the UCLA Loneliness Scale (ULS, version 3) (Russell, 1996). There are

no published test-retest reliability scores for the de Jong-Gierveld Loneliness Scale although it is useful in correlating to aspects of common loneliness such as low self-esteem. The SELSA is a well-used measure with good internal consistency and looks at both social and emotional aspects of loneliness. However the questionnaire consists of 37 items and as there was already a large battery of questionnaires, it was felt that a more succinct measure would be preferable. The ULS Version 3 was therefore chosen as the measure of loneliness and isolation. The reasons for this choice are outlined below.

The ULS has become the most widely used tool for gauging loneliness across both general and clinical populations (Oshagan & Allen, 1992; Russell, 1996; Durak et al., 2010) and is not solely based on looking at the availability of support systems. This is pertinent to this study as it was felt that the participants might feel lonely even within a wider system due to other people's lack of understanding their day-to-day experience.

The ULS (Version 3) offers a simple and reliable means of assessing loneliness, comprising 20 items, offering a total score of general loneliness. The measure has a high internal validity with coefficient alphas ranging between 0.89 and 0.94 (Russell, 1996) and a good test-retest reliability score of 0.73 over a period of 12 months. There also appears to be good construct validity, with high correlations being found between the UCLA Loneliness Scale and other loneliness scales including self-reporting of loneliness (Russell, 1996; Russell, Peplau & Cutrona, 1980).

#### *3.1.1.5 Coping*

Coping is a complex construct that has previously been defined as how a person reacts during a highly emotive situation (Lazarus, 1991). It appears to be difficult to find an overall measure of coping owing to there being both passive and active means of coping. Some measures, such as the Mainz Coping Inventory (Krohne, 1993) offer hypothetical situations to gauge how people would manage in differing emotional situations. As the current study requires participants to reflect upon how they cope with their child's feeding disorder, it did not seem useful to employ such measures. Both the COPE

Scale (Carver, Sheier & Weintraub, 1989) and the Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990) were considered for use because of their reflection of the complexity of coping mechanisms; however both measures are lengthy to complete. The Brief COPE (Carver, 1997), a shortened version of the COPE was selected for use. It is a self-report measure comprising 28 items (14 subscales) that assess the various coping strategies employed by people following a stressful event or ongoing situation. These include subscales that have statements depicting strategies such as; distraction, denial, use of both practical and emotional support and acceptance. Each item is answered on a scale of 1 to 4 indicating how often they employ a particular coping strategy. Carver (1997) found coefficient alphas ranging between 0.57 and 0.90. A more recent study by Benson (2009) reported a coefficient alpha of between 0.54 and 0.93 when looking at coping styles in parents of young children.

Carver (1997) stated that he purposefully has not divided the coping styles into active versus passive coping or problem-based coping versus emotion-based coping or adaptive/maladaptive coping, nor does he offer an overall measure of 'coping'. His preference is to look at each subscale separately in relation to other variables and recommends that individual researchers group coping styles together themselves if it is necessary for the study. Instead of scoring the 14 individual subscales in a 28 item questionnaire, within this study, it was felt to be more meaningful to look at coping styles, i.e. active or passive coping, rather than individual coping strategies, for example 'I've been trying to find comfort in my religion or spiritual beliefs'. It was therefore decided by the researcher to score the items in to two styles of coping 'active' versus 'passive'. The items that were considered to fall into 'active coping' were items; 2,5,7,9,10,12,14,15,17,21, 22,23,25,27 (Appendix 4). The items considered as passive coping for the purpose of this study were; 1,3,4,6,8,11,13,16,18,19,20,24,26,28. Active coping has been previously defined as; finding a means to alter the situation, seeking support and developing a positive meaning from the situation, often spiritual in nature. Passive coping has been defined as finding a means of becoming detached from the situation in order to reduce the impact, blaming oneself or avoiding

the situation entirely (Folkman & Lazarus, 1988; Patterson et al., 1993).

#### *3.1.1.6 Feeding Disorder Severity*

There are a small range of feeding disorder assessment tools including the Early Feeding Skills (EFS) assessment (Thoyre, Shaker and Pridham, 2005), the Neonatal Oral-Motor Assessment Scale (NOMAS) (Braun & Palmer, 1986) and the BPFAS (Crist et al., 1994). The EFS is useful at determining the child's physical ability to feed rather than gaining an understanding of the range of physical and psychological processes at play in the case of disordered feeding. The NOMAS similarly looks at physical feeding ability. The BPFAS (Appendix 6) which is the assessment tool used within the GOSH feeding disorder team looks more broadly at the range of issues that can impede 'typical' feeding, such as tube feeding or disruptive mealtime behaviours. The assessment also includes the parental experience of the child. It is validated for use for children who are 0-8 years of age, which is representative of the children seen in the service where the research was conducted. This tool was used within the current study, but was not a part of the research pack, as the parents had been asked to complete the questionnaire prior to initial assessment at the service.

#### *3.1.1.7 Demographic Questionnaire*

A demographic questionnaire (Appendix 5) was designed by the researcher in order to gather information on the backgrounds of the child and family, the age of the child and parents, whether there were siblings in the home, the marital status of the parents and the family's religion/ethnicity.

The mid-section of the demographic questionnaire related to whether there was a history of mental health difficulties or eating disorders for either the mother or father as the presence of previous mental health problems might be a factor in how the parents managed the current stressor of their child having a feeding disorder. Previous research by Bayliss, Meyer and Haycraft (2006) indicated that parental mental health problems are often related to negative interactions when feeding their child. Maternal eating disorders in particular have been found to be linked with feeding difficulties in children with studies

showing that there are often higher levels of intrusive and negative interactions during meals (Coulthard, Blissett & Harris, 2004). Mothers or fathers with previous eating disorder histories may find they are impacted to a greater extent than those without and this may need to be a factor that is taken into account in parent groups.

The latter part of the questionnaire focused on factors relating to the child, for example if they were tube fed, if they have an underlying medical issue that was related to the feeding disorder or whether the parents believed that their child's feeding difficulty was due to emotional or behavioural reasons. Further questions related to presence of an Autism Spectrum Disorder or a developmental delay were also asked, as there is usually a higher occurrence of feeding disorders within this population. The information regarding the perceived origin of the feeding disorder and the level of developmental delay/presence of ASD was based on parental report rather than the assessment of clinicians at GOSH. It therefore must be noted that the understanding of the child's feeding disorder is based on subjective parental report not objective assessment.

These questions related to whether parent groups might need to be divided according to the origin of the child's feeding problem, as the parents might be impacted differently according to whether their child's feeding disorder is considered to be a part of a wider issue such as a developmental delay or whether the parents perceived it to be due to emotional/behavioural factors.

## **3.2. Ethical Considerations**

### **3.2.1. Possible Distress Caused and Identification of Further Problems**

The researchers were aware that the questionnaires might touch on issues that might cause upset to some participants and therefore were available to be contacted if any issues arose. Participants would also be advised to speak to the clinician involved in their child's care. It was explained to participants that if any issues relating to risk arose, they would be shared according to

NHS guidelines. The information sheet contained the researchers contact details and outlined all the options available to the participants and the researchers.

If the participants scored above the clinical cut off on the BDI they were informed both orally and on the information sheet that the clinician involved in their child's care would be made aware. It was also noted that if it was felt necessary, the clinician might advise a referral to the GP regarding parental low mood. The participant was asked for their consent for this to occur and it would not be done without consent and discussion with the clinician in charge of their child's care. In cases where this occurred the correct procedure was followed.

Owing to the nature of the difficulties faced by children of the participants, the researchers were aware that participants might be stressed and short of time. The questionnaire battery took approximately 45minutes to complete. If a participant wished to withdraw from the study at any time, they were informed that they were able to do so without explanation. It was requested that they inform the researcher that they wished to withdraw in order that they were not contacted again.

### 3.2.2. Storage of Data

Data storage was in line with NHS and data protection guidelines. All data from the participants was anonymised and coded. Any identifying data was kept separately. All data was kept in locked storage facility when not in use. Only the researchers had access to the data.

### 3.2.3. Confidentiality and Consent

Patients attending the service were given information sheets outlining the research prior to their consenting to take part in the study. It was clearly stated in the information given that they were under no obligation to take part in the study and participation or non-participation would not affect their child's treatment in any way. The participants were told that they were free to withdraw from the study at any time if they wished to do so without impacting



on their child's care. It was felt important that parents did not feel coerced into taking part in the study, therefore once the questionnaire had been sent out, it was agreed that there would be only one follow up phone call to act as a reminder, however it was not to be used as an attempt to persuade them to take part.

The consent form was included with the questionnaire pack and information pack. Each element of the study that the participants were agreeing to was outlined clearly on the consent form, with a space for a signature to ensure that the researcher was aware if there were any aspects of the study in which they did not wish to partake, for example, the researcher accessing patient files to gather any missing information.

#### 3.2.4. Ethical Approval

Ethical approval was sought and granted by the University of East London Ethics Committee, the NHS Research Ethics Committee at Chelsea and Westminster Hospital, Great Ormond Street Hospital for Children Research Ethics Committee and Research and Development Approval was granted by Great Ormond Street Hospital for Children NHS Trust (Appendices 7-9).

### **3.3. Procedure**

#### 3.3.1. Participant Recruitment

Parents of children aged 0-8 years attending the Great Ormond Street Hospital Feeding Disorder Service were approached face-to-face either during an assessment session or at a treatment appointment regarding taking part in the study. Some parents were approached via letter outlining the research if they were not due to attend the service during the recruitment period. Each set of parents (or parent, if attending alone) was given the information sheet alongside a pack of questionnaires and consent forms for both the mother and the father.

It was explained that both mothers and fathers would each receive a set of five questionnaires regarding areas that had been previously identified as

being potentially relevant in parenting a child with a feeding disorder. Parents were asked for basic demographic information regarding themselves and their child. Parents had previously been asked to complete the BPFAS on attending the service for initial assessment (Crist et al, 1994) as a measure of perceived severity of their child's feeding problem. This was considered routine practice within the service. Opportunity to discuss any questions was provided as part of the process of seeking consent. The researcher's contact details were made available on the information sheet and participants were also able to call a researcher directly at the service.

The parents were asked to read the information sheet fully prior to deciding whether they would like to take part in the study. They were advised that they were able to take the pack home if they were pressed for time following their assessment or treatment appointment. They were advised that they could ask questions prior to taking part in the study or if they had questions whilst completing the questionnaire, they could ask at the end of their appointment or could call the researcher during the week and they would be responded to, at the earliest possible time. Each questionnaire had written instructions, showing the participant how to complete each section. The questionnaires were given together with a stamped addressed envelope if they wished to return the packs by post, or they could bring the completed packs to their next appointment. Mothers and fathers had separate envelopes, as they might not wish for their partner to see the responses to the questions asked.

It was hoped that approximately 40 sets of mothers and fathers would be recruited to take part in the research. A previous study of a similar nature (Piepenstock, 2010) achieved highly powered analyses in regressions including parental factors and child feeding (e.g. effect size of 0.37 and power of 0.94) with 42 sets of parents. Owing to the current study being exploratory, and geared towards developing content for a parent intervention rather than hypothesis testing, it was not indicated to perform a power calculation, as it was not possible to determine the effect size that was being aimed for. It seemed realistic to aim for a similar sample size to a previous study within the service.

No control group was needed as the study was not experimental, rather it was exploratory and the aim was to identify differences in relevant areas to address within a heterogeneous clinical population. Once the questionnaires were returned, parents were not asked for any further participation. The parents of the patients were asked to give their home addresses on their consent form if they wished to receive a brief outline on the outcome of the research on its' completion. Participants were informed that no identifying information would be used within the research and they were able to ensure no identifying data could be seen on the questionnaires and they were able to fill out the forms in total anonymity if they so wished.

### 3.3.2. Inclusion Criteria

Parents of children referred to and accepted for assessment and/or treatment at Great Ormond Street Hospital Feeding Disorder Service were the initial inclusion criteria. For the purpose of this study it was important questionnaires were completed by both parents of the presenting child. Therefore only families where both the mother and father were involved in the child's care were recruited to take part. The parents did not need to be married or living together. Both foster and adopted parents of children attending the service were eligible to be included in the study.

As the study looks at what factors impact on the parents of a child with feeding disorders, children with co-morbid medical or developmental difficulties were included in the study. This was felt to be highly representative of the sample.

The BPFAS (Crist et al., 1994) looks at perceived symptom severity and has norms for children aged 0-8. It was decided that the study would include parents of children between 0 and 8 years of age. However if parents completed the initial BPFAS when the child was within this age range, exceptions were made. In order to take part in the study the parents and child had to have attended the service for under a year and not taken part in any previous research projects within the service.

### 3.3.3. Exclusion Criteria

Parents of children outside the age range of 0-8 years were excluded owing to both the service at GOSH being primarily offered to children within this age range and the BPFAS being valid for children between the ages of 0-8 years. As much of the study was based on developing an understanding of what difficulties both mothers and fathers experience when parenting a child with a feeding disorder, single sex parent couples were excluded from taking part. Families where only one parent was involved in the care of the child were also excluded from the study. Being questionnaire based, it was not possible to include in the study parents who did not read or speak enough English to complete the questionnaires, as not all the questionnaires were available in a range of languages. Parents of children who had been attending the service for treatment for over a year were also excluded from the study, as many of their issues may have been addressed and their responses may not have been representative of how they felt either at the start or early on in their child's treatment.

## **3.4. Participant Information**

### 3.4.1. Demographic Information and Raw Scores

The research sample was made up of 36 matched pairs of mothers and fathers of children presenting with feeding disorders at a national specialist feeding disorder service.

#### *3.4.1.1. Child factors*

The mean age of the referred children in the study was 3.83 years (SD = 1.86), with the youngest child being 1 year old and the oldest being 9 years of age (It was decided that the 9 year old child could be included as he had only recently turned 9 and commenced his treatment at 8 years of age). There were 19 male children (52.8%) and 17 females (47.2%).

#### *3.4.1.2. Developmental delay and Autism*

From the sample of children 20 (55.6%) were considered by parental report to have a developmental delay and 16 children (44.4%) were reported not to

have any developmental delay. Eight (22.2%) of the 36 children attend specialist schools and 4 (11.1%) of the children had been diagnosed with an Autism Spectrum Disorder (see Table 3.1 below).

**Table 3.1:** Percentage of children reported to have a developmental delay and the severity of the delay as reported by parents.

<b>Severity of Developmental Delay</b>	<b>Number of Children</b>	<b>Percentage (%) (2.8% = 1 person)</b>
<b>None</b>	16	44.4
<b>Mild</b>	6	16.7
<b>Moderate</b>	10	27.8
<b>Severe</b>	4	11.1

#### *3.4.1.3. Medical problems, tube feeding and emotional behavioural factors*

Of the 36 children in the sample 18 (50%) had either been tube fed in the past or were tube fed at the time of the study. 29 children (80.6%) were considered to have an underlying medical problem related to their feeding difficulties. Of the 36 children, parents felt that 15 children (41.7%) could have their feeding disorder attributed in part to emotional and behavioural factors.

#### *3.4.1.4. Maternal factors*

The mean age for mothers was 36.6 years, with the youngest being 23 and the oldest being 47 years of age. Of the 36 mothers, nine (25%) disclosed that they have had a previous or ongoing mental health problem. Four mothers (11.1%) stated that they previously had an eating disorder.

#### *3.4.1.5. Paternal factors*

Within the father sample the mean age was 39.53, with the youngest father being 22 and the oldest father being 55 years of age. Of the sample only one father (2.8%) stated a history of mental health problems and two fathers (5.6%) stated that they had previously had an Eating Disorder.

### 3.4.1.6. Joint parent factors

**Table 3.2:** Religious beliefs of the parent sample

<b>Religion</b>	<b>Number of Parents</b>	<b>Percentage (%) (2.8% = 1 person)</b>
Catholic	2	5.6
Christian	10	27.8
Christian Orthodox	2	5.6
Jewish	2	5.6
Muslim	4	11.1
Hindu	3	8.3
None	6	16.7

**Table 3.3:** Recorded ethnicities of the parent sample

<b>Ethnicity</b>	<b>Number of Parents</b>	<b>Percentage (%) (2.8% = 1 person)</b>
<b>Arabic</b>	1	2.8
<b>British</b>	1	2.8
<b>European</b>	1	2.8
<b>Indian</b>	1	2.8
<b>Mauritian</b>	1	2.8
<b>Oriental</b>	1	2.8
<b>Pakistani</b>	1	2.8
<b>White</b>	2	2.8
<b>White British</b>	19	52.8
<b>White Ukranian</b>	1	2.8
<b>White/Asian</b>	1	2.8
<b>Not Specified</b>	6	16.7

**Table 3.4:** Marital status of parent sample

<b>Marital Status</b>	<b>Number of couples</b>	<b>Percentage (%) (2.8% = 1 person)</b>
<b>Married</b>	28	77.8
<b>Co-habiting</b>	7	19.4
<b>Divorced/Separated</b>	1	2.8

#### *3.4.1.7. Summary of participant descriptive factors*

In the child sample the average age was 3.84. Twenty children were reported by parents to have a developmental delay, and four children with a diagnosis of an Autism Spectrum Disorder. From the raw data one is able to see that a number of the children have both developmental delays and medical problems related to feeding (i.e. reflux, tube feeding, gastro-intestinal problems and severe intolerance of certain foods), with medical problems affecting 80% of the sample and 50% of the children having been tube-fed at some point in their lives. Forty-one percent of the parents attributed (to some extent) their child's feeding disorder to emotional and behavioural difficulties. It was rare that parents attributed the feeding disorder solely to emotional and behavioural difficulties, indicating that they were perceived as secondary to developmental delay or physical discomfort.

Of the mothers, nine (25%) reported previous or ongoing mental health difficulties, this is in line with the general population, where 29% of women in the UK are reported to have been treated for mental health problems (Office of National Statistics, 2003). Four (11%) reported having a previous history of an eating disorder, this is in line with the incidence of eating disorders in the UK (approximately 10% of women suffer from eating disorders across their lifetime) (ANAD, 2015). Of the fathers, one disclosed having mental health difficulties, this is noticeably fewer than the general population, where 17% of men are reported to need treatment for mental health difficulties (Office of National Statistics, 2003). Two fathers reported having a history of eating disorders. Owing to the small percentage of fathers disclosing a mental health problem, this information was not entered into the further analysis. It is

possible that fathers under-reported experiences of mental health difficulties. This is in line with a study by Harris (2001), where the author hypothesises that men find it difficult to disclose their feelings until they present more severely and are under duress to do so. Whilst the level of eating disorders in men does not appear to be an under-representation of eating disorders in the general male population (approximately 1%) (ANAD, 2015), as the number within the study was small, it was also excluded as a predictor variable.

There was a wide range of religions and ethnicities within the sample population with the largest religious group being Christian (33.4%), followed by no religion stated (16.7%) with Muslims, Jews, Catholics and Hindus each making up between 5.6 and 11.1% of the population. There was also a wide range of ethnicities amongst the clinical sample, with the largest group being white British (52.8%). Owing to the wide spread of religions and ethnicity in the parent sample, the information was not used in any further analysis. It was not thought appropriate to place 'other' religions and ethnicities into wider groupings, as each religion and ethnicity is distinct and unique and would therefore not give meaningful results if placed together.

There were 72 sets of parents who were approached to take part in the study. 38 questionnaire packs were returned, however there were two sets of questionnaires that were unable to be used in the study as only the mothers had returned the questionnaires. Therefore 36 parent couples were eligible to be included in the study, indicating that only 50% of the parents approached actually took part in the study.

### **3.5. Data Analysis**

- In order to investigate the impact of having a child with a feeding disorder, a series of simple calculations were completed to show how many mothers and fathers reached moderate to severe outcomes on each of the five identified variables. This included calculating how many mothers and fathers scored above either a clinical cut-off score



or that dictated by the questionnaire itself (i.e. the thresholds for mild, moderate and severe depression) or the cut off decided by the researcher, in line with previous studies using the same tools.

- The BDI scores mild depressive symptoms as 14-19; moderate symptoms between 20-28 and severe symptoms between 29-63 (Beck & Steer, 1996). For the purpose of this study, scores above 19 were considered above 'cut off' for clinical significance.
- The BAI denotes mild anxiety as scores between 8-15, moderate 16-25 and severe anxiety between 26 and 63 (Beck et al., 1990). For the purpose of this study scores above 16 were considered above 'cut off' for significance.
- The UCLA Loneliness Scale cut off for 'significant' loneliness scores was 42 (Russell, 1996).
- A cut off of 14 (50%) on both the active and passive COPE subscales was decided on by the researcher as a means of understanding whether a particular coping style was employed by the individual. This must be interpreted with caution, as there is no cut off score indicated on the Brief COPE.
- Scores of above 90 (above the 90<sup>th</sup> percentile) are considered clinically significant on the PSI-SF (Abidin, 1990).
- To investigate the differences between mothers and fathers on the five identified parent variables, a series of Wilcoxon Rank Tests were used. These tests offer an indication of whether mother and father scores were significantly different from one another.
- A General Linear Model was conducted to investigate the impact of the predictor variables (child age; symptom severity; type of feeding disorder; developmental delay; ASD and parent factors) on each of the five independent variables. Cohen's Effect Sizes were used in order to identify possible associations between the predictor variables and the independent variables. It was decided not to employ the use of p-values, as the significance levels are so highly dependent on the sample size. It will be noted in the discussion that as p-values were not used, the results must be understood with relative caution.

- A power calculation was not indicated as being meaningful within this study, as the aim of the study is to develop content, rather than test null hypotheses. The study was also less susceptible to Type I and Type II errors, as no specific hypotheses were being tested.

## 4. RESULTS

### 4.1. Exploratory Data Analysis

Prior to carrying out a series of analyses on the data, exploratory statistics were completed to ensure that the data satisfied the assumptions of the normality of the data. The histograms in Appendix 9 give an indication of whether the tests for normality were satisfied and whether any modifications needed to be made. The results of the exploratory data and for each of the research aims are described below.

**Table 4.1:** Table to Show Age of Parent Participants, Parent Scores, Skewness and Kurtosis

	Mean	Std. Deviation	Min.	Max.	Skewness SE = .393	Kurtosis SE = .768
Mother Age	36.60	5.435	23	47	-.597	.192
Father Age	39.53	6.839	22	55	-.138	.475
BDI Mother	10.33	9.375	0	39	.996*	.905*
BDI Father	7.08	9.327	0	30	1.261*	.339
BAI Mother	8.47	6.831	0	28	.978	.700
BAI Father	4.14	6.058	0	23	1.848*	2.918*
Coping Active Mother	31.00	6.899	16	43	-.245	-.661
Coping Active Father	26.25	6.276	14	40	.234	-.456
Coping Passive Mother	22.53	3.865	14	29	-.053	-.318

Coping Passive Father	20.56	3.722	14	31	.337	.720
Loneliness Mother	40.17	12.068	20	64	.400	-.679
Loneliness Father	35.42	12.422	20	67	.763	-.299
PSI Total Mother	85.61	23.361	39	136	.407	-.277
PSI Total Father	76.11	21.226	40	130	.649	.234

\* Denotes significant Skewness or Kurtosis

**Table 4.2:** Table to Show Shapiro-Wilk Test for Normality

Variable	Statistic	Degrees of Freedom	Significance
Mother Age	.968	35	.384
Father Age	.987	36	.941
BDI Mother	.905	36	.005*
BDI Father	.766	36	.000*
BAI Mother	.917	36	.011*
BAI Father	.723	36	.000*
Coping Active Mother	.974	36	.531
Coping Active Father	.978	36	.693
Coping Passive Mother	.972	36	.472
Coping Passive Father	.971	36	.440
Loneliness Mother	.960	36	.222
Loneliness Father	.918	36	.011*
PSI Total Mother	.975	36	.570
PSI Total Father	.955	36	.149

\* Denotes significance at the  $p = 0.05$  level, thereby not reaching criterion for normality

Exploratory data analysis was carried out in order to establish whether there were any significant outliers in the sample (see Appendix 10 for histograms of exploratory data analyses). Prior to carrying out any analysis, participants 16 and 37 were removed from the data set as the father's scores were missing. Therefore there were 36 complete sets of data to use for analysis. It was clear from 'eyeballing' the raw data that there was an extreme outlier for one of the maternal BDI scores. As the results for maternal BDI were not normally distributed, this piece of data remained within the data set and the data was transformed using a Blom's transformation (Blom, 1958). A Blom's transformation was used as the data set was relatively small and as multivariate tests assume normality; this enables further analysis to be conducted as it transforms the variables to reach normality. The Blom transformation replaces each raw score by its rank approximation to the exact order of a normal distribution:  $Y_i = \Phi^{-1}[(r_i - \frac{3}{8}) / (n + \frac{1}{4})]$  where  $\Phi^{-1}$  is the inverse cumulative normal function,  $r_i$  the rank of observation  $i$ , and  $n$  the number of non-missing observations. For all variables this yielded normalized scores with acceptable parameters for analysis (skewness <1, kurtosis <2, Shapiro-Wilk  $p > .1$ ).

The data was further explored visually through a series of histograms (Appendix 9, figures 3.1 – 3.12). The skewness and kurtosis of each data set was also explored in order to assess whether there were any negative skews (table 3.1). On examination of the scores, it was found that both the maternal and paternal BDI scores were significantly skewed due to outliers. In order to use this data for further analysis, the value of the data needed to be transformed in order to correct for the skew and not meeting criteria for 'normality'. The data was therefore transformed by using a Blom's transformation. The data for the paternal BAI was also significantly skewed; however the data for the maternal BAI scores was not. However, in order to enable correct comparison between maternal and paternal BAI scores, a Blom's transformation was carried out on both data sets.

By transforming the data on the BDI and BAI data sets the significant skew was resolved and on re-examination of the data, the skewness and kurtosis of

the transformed data showed that the scores were normally distributed (see table 4.3 below).

**Table 4.3:** Table to Show 'Normal' Scores of Transformed Data for Further Statistical Analysis

	Mean	Std. Dev	Min.	Max.	Skew (SE = .393)	Kurtosis (SE = .768)
Normalised Mother BDI	.0115	.9466	-1.458	2.114	.162	-.553
Normalised Father BDI	.0349	.8932	-.958	2.114	.452	-.708
Normalised Mother BAI	.0108	.9472	-1.458	2.114	.157	-.551
Normalised Father BAI	.0451	.8669	-.805	2.114	.596	-.663

## 4.2. Summary of exploratory data analysis

Following exploratory data analysis and transforming the data on the BDI and BAI mother and father scores, the data shows a normal distribution curve and met the criterion for parametric statistical analysis.

## 4.3. Results of Research Aim One

Research question one looks at how mothers and fathers are impacted by their child's feeding disorder across five variables identified as being pertinent to this population. These include; depression as measured by the BDI; anxiety as measured by the BAI; coping styles as measured by the COPE; loneliness as measured by the UCLA Loneliness Scale and parenting stress as measured by the PSI-SF. The mean scores for mothers and fathers on each variable will be reported, alongside the number of mothers and fathers who scored above 'cut off' for significance on each of the variables. The cut-off scores for significance were detailed in section 2.5 and can be seen in the key of table 4.4 below.

**Table 4.4:** Table to show the mean scores of mothers and fathers on each of the variables and how many parents showed scores above cut off.

<b>Variable</b>	<b>Mean Score (Mother)</b>	<b>Standard Deviation</b>	<b>Mean Score (Father)</b>	<b>Standard Deviation</b>	<b>No. of Mothers Showing Scores Above Cut-off (%)</b>	<b>No. of Fathers Showing Scores Above Cut-off (%)</b>
<b>BDI</b>	10.00	8.49	7.08	9.32	6 (16.6)*	6 (16.6)*
<b>BAI</b>	8.47	6.83	4.14	6.05	7 (19.4)**	3 (8.3)**
<b>Passive Coping (COPE)</b>	31.00	6.89	26.25	6.27	5 (13.8)***	1 (2.7)***
<b>Active Coping (COPE)</b>	22.53	3.86	20.56	3.72	23 (63.8)***	14 (38.8)***
<b>UCLA Loneliness Scale</b>	40.17	12.06	35.42	12.42	14 (38.8)****	11 (30.5)****
<b>PSI-SF</b>	85.61	23.36	76.11	21.22	13 (36.1)*****	8 (22.2)*****

\* BDI scores below 19 = below what would not be considered to meet diagnostic criteria for depression, scores above 19 would be considered to reach clinical significance in addition to clinical assessment.

\*\* BAI scores below 16, do not meet diagnostic criteria for Anxiety disorders, scores above 16 are considered clinically significant in addition to clinical assessment.

\*\*\* Scores above 14 (50%) on either active or passive coping on the Brief COPE was decided upon to indicate higher levels of use of either coping style.

\*\*\*\* Scores above 42 on the UCLA Loneliness Scale indicate 'significant' loneliness.

\*\*\*\*\* A total score on the PSI-SF of above 90 is considered 'clinically significant parenting stress'.

**Table 4.5:** Table to show matched mother and father raw scores on the five variables.

M BDI Raw Score	F BDI Raw Score	M BAI Raw Score	F BAI Raw Score	M Passive COPE Score	F Passive COPE Score	M Active COPE Score	F Active COPE Score	M Loneliness Score	F Loneliness Score	M PSI – SF Score	F PSI - SF Score
23	28	9	5	25	19	35	28	43	52	82	66
13	0	16	0	26	19	26	26	42	21	62	42
26	14	4	5	29	31	33	28	62	50	123	119
4	2	8	1	18	21	20	17	34	21	71	64
12	22	16	16	24	24	26	26	44	46	109	113
21	22	28	9	29	22	36	27	64	54	135	107
1	0	9	7	27	26	33	31	24	25	83	108
8	13	8	6	19	21	32	26	36	30	64	71
1	1	0	6	18	22	41	40	22	22	64	64
9	0	8	0	21	19	36	32	26	20	73	55
23	13	18	5	29	22	33	23	52	45	102	77
25	9	8	3	19	18	28	25	62	39	122	86
12	3	15	0	20	23	33	28	45	26	108	84
9	6	7	0	20	18	31	26	30	25	66	63
1	0	0	0	22	20	35	32	42	39	57	55
0	0	0	0	14	15	19	21	20	24	39	40
4	0	0	0	21	21	36	36	33	33	76	71
12	4	16	3	25	25	38	37	38	35	103	97
15	21	22	12	23	23	43	29	46	45	89	94
9	10	13	14	17	16	23	18	38	46	79	69
0	0	11	1	26	23	32	31	34	34	67	62
27	0	6	0	29	14	26	14	58	30	117	66
5	30	3	21	22	20	24	22	36	67	88	84
1	0	2	0	24	17	30	22	32	30	98	64
0	2	10	0	23	21	27	24	26	24	54	58
0	1	5	5	22	24	35	36	28	26	61	69
0	4	3	2	15	14	16	18	32	29	74	62
17	5	7	2	22	18	22	18	50	46	101	80
4	1	4	0	21	14	33	18	30	26	58	43
4	2	0	1	20	20	26	24	41	32	78	73
11	0	5	0	24	20	39	22	41	22	87	81



18	0	21	0	22	22	22	22	60	38	136	130
5	0	6	0	20	18	37	33	41	24	92	65
17	14	3	2	24	23	27	25	54	59	92	94
6	1	8	0	28	20	41	25	28	34	85	83
17	27	6	23	23	27	42	35	52	56	87	81

Whilst in some couples there appeared to be consistency in whether scores were higher or lower across both parents, there are a number of couples where one partner scores particularly highly and the other displaying a lower score. It is therefore a possibility that maternal and paternal experiences can differ greatly even within the same family context.

#### 4.3.1. Summary of Research Aim One

It was of note was that as many fathers as mothers showed high scores on the BDI (six fathers and six mothers). As this parent sample is considered a non-clinical, this cannot be used as diagnostic information, however it indicates the extent of the emotional impact on both parents of having a child with feeding disorders.

Seven mothers and three fathers scored above the cut-off score for anxiety, although more mothers were moderate-severely affected by anxiety, fathers were also impacted.

Many more mothers than fathers scored above the cut off for both types of coping. Twenty-three mothers scored above cut off for active coping and five for passive coping, as compared to fathers, where 14 scored above cut off for active coping and one for passive coping. This indicates that mothers employ a greater use of coping strategies than fathers, whether active or passive, but especially active coping techniques.

Approximately a third of both mothers and fathers expressed feeling socially isolated indicating a need when developing skills and support groups for both parents. A high number of mothers (36.1%) and fathers (22.2%) scored above cut-off for parent stress, in relation to their child with a feeding disorder.

Overall, these scores indicate that the experience of having a child with a feeding disorder does not only affect the mother, but fathers are also impacted.

#### 4.4. Results of Research Aim Two

The second research aim was to understand whether mothers and fathers were impacted differently on a range of variables previously associated with having a child with a feeding disorder. The variables included, depression, anxiety, parenting stress, coping and loneliness. Because fathers of children with feeding disorders have rarely been included in previous research and the current research is exploratory, there was no directional hypothesis.

As some of the raw data did not meet the criteria for tests of normality, non-parametric tests were used to examine the differences between the data. Wilcoxon tests were carried out to explore whether mothers and fathers showed significant differences across the five identified variables and in which direction the differences lay.

**Table 4.6:** Table to Show the Difference between Mother and Father Scores on each of the Identified Variables using a Wilcoxon's Signed Ranks Test

	BDI Father - BDI Mother	BAI Father - BAI Mother	Coping Active Father - Coping Active Mother	Coping Passive Father - Coping Passive Mother	Loneliness Father - Loneliness Mother	PSI Total Father - PSI Total Mother
Z	-2.084	-3.276	-4.616	-2.501	-2.601	-3.548
Asymp. Sig. (2- tailed)	.037*	.001*	.000*	.012*	.009*	.000*

\* denotes a significant difference between mother and father scores

#### 4.4.1. BDI

Mothers and fathers were compared on the BDI using a Wilcoxon's Signed Ranks Test for related samples. Mothers scored significantly higher on the BDI than fathers ( $Z(35) = -2.08$ , Exact sig (2-tailed) = .036). This indicated that mothers experienced significantly more symptoms of depression as compared to matched fathers.

#### 4.4.2. BAI

Mother and father scores were compared on the BAI using Wilcoxon's Signed Ranks Test for related samples. There was a significant difference between mother and father scores on the BAI ( $Z(35) = -3.28$ , Exact sig (2-tailed) = 0.001). This indicated that mothers of children with feeding disorders were significantly more anxious than matched fathers.

#### 4.4.3. Active Coping Subscale – Brief COPE

Mother and father scores were compared on the active coping subscale of the COPE using a Wilcoxon's Signed Ranks Test for related samples. Mothers were found to use significantly more active coping strategies than matched fathers ( $Z(35) = -4.62$ , Exact sig (2-tailed) = 0.00). This indicates that mothers use significantly more active coping strategies (for example; more support networks, strategizing about how to find solutions and taking advice) than matched fathers.

#### 4.4.4. Passive Coping Subscale - Brief COPE

Mother and father scores were compared on the passive coping subscale of the COPE using a Wilcoxon's Signed Ranks Test for related samples. Mothers were found to use significantly more passive coping strategies than matched fathers ( $Z(35) = -2.50$ , Exact sig (2-tailed) = 0.012). This includes actions such as denial of the situation or being unpleasant to others as a means of letting one's feelings out. The results indicate that overall fathers use significantly less coping strategies than mothers, whether active or passive.

#### 4.4.5. UCLA Loneliness Scale

Mother and father scores were compared on the UCLA Loneliness Scale using a Wilcoxon's Signed Ranks Test for related samples. Mothers were found to express significantly more loneliness than fathers ( $Z(35) = -2.60$ , Exact sig (2-tailed) = 0.009). This subscale deals with issues such as how often does the individual feels they have had someone to turn to, or feeling left out or not understood by others around them.

#### 4.4.6. PSI-SF

Mothers and fathers total scores were compared on the PSI-SF Wilcoxon's Signed Ranks Test for related samples. Mothers scored significantly higher on the PSF than fathers ( $Z(35) = -3.55$ , Exact sig (2-tailed) = 0.00). This indicated that mothers of children with feeding disorders experience more parenting stress than fathers; however this is not to say that fathers do not experience parenting stress only that it is to a lesser degree than mothers.

#### 4.4.7. Summary of Research Aim Two

Mothers scored significantly higher on the BDI; BAI; active and passive coping subscales on the COPE; UCLA Loneliness Scale and the PSI-SF. Whilst there was no directional hypothesis due to the exploratory nature of the study, it was considered likely that mothers and fathers would have differing responses on some or all of the identified variables, which appears to be the case on all the five variables. This assumption is based on previous studies including the study by Piepenstock (2010), where although fathers were identified as experiencing greater parenting stress in feeding disordered families as compared to controls, they experienced significantly less parenting stress than matched mothers. The possible reasons for the difference and directionality of the difference will be considered in detail in the discussion.

### **4.5. Results of Research Aim Three**

The third research aim was to explore whether the focus of parent interventions may have to differ according to characteristics of the child's

presentation, for example; age, type of feeding problem (medical/non-medical; ASD/no ASD; tube fed/ no tube; emotional/behavioural), and severity of feeding disorder. Some parent characteristics were also considered, these included a history of mental health problems or eating disorders in mothers. Father characteristics were not included, as there were not enough fathers who noted having a history of mental health or eating disorders. Due to the exploratory nature of the research, no directional hypotheses were made.

In order to gain a better understanding of what the main issues that impact on parents of children with feeding disorders were, a multivariate General Linear Model (GLM) was generated. This enables all the possible predictor variables to be entered into a multivariate GLM analysis with the five dependent variables (BDI, BAI, Brief COPE, UCLA Loneliness Scale and PSI). Mothers and fathers were entered into separate GLMs. The outcome of the GLMs offers information on how much variance is accounted for in each of the dependent variables, by the predictor variables. It therefore shows which aspects of child and parent characteristics are most likely to impact on depression, anxiety, coping, loneliness and parent stress. With this information, it may be possible to determine whether parent groups need to be tailored according to child (and parent) characteristics. Owing to the multivariate nature of the analyses, a partial Eta was calculated; this shows the proportion of the variance that a variable explains, that cannot be accounted for by another variable.

Owing to the relatively small sample size, Cohen's effect sizes (1988) were used as a measure of assessing whether the percentage variance was 'significant', rather than whether the predictors reached significance at the 0.05 level.

#### 4.5.1. Predictors of Depression in Mothers

In order to analyse which factors predicted maternal scores on the BDI, all chosen predictors were loaded into a multivariate GLM (which included all five dependent variables). The predictor variables included: symptom severity as measured by the BPFAS; emotional/behavioural origin of feeding disorder;

age of child; medical problem; tube feeding (past or ongoing); presence of an ASD, presence of a developmental delay in the child and previous or ongoing maternal mental health or eating disorders in mothers.

Within the mother sample, six variables accounted for large amounts of variance in maternal reported depression. Child age accounted for a unique and large amount of variance ( $B = .141$ ,  $t = 1.441$ ,  $\eta^2 = .172$ ,  $p = .180$ ), as did the child's symptom severity as measured by the BPFAS, ( $B = .039$ ,  $t = .029$ ,  $\eta^2 = .150$ ,  $p = .214$ ) and no presence of a medical problem in the child ( $B = .3.622$ ,  $t = 2.452$ ,  $\eta^2 = .179$ ,  $p = .170$ ). Each of these predictor variables accounted for between 15-18% of the variance in maternal reported depressive symptoms.

The presence of tube feeding in the child had a significant and unique contribution to maternal reported depressive symptoms ( $B = - 6.262$ ,  $t = 2.600$ ,  $\eta^2 = .367$ ,  $p = .037$ ). The presence of an ASD in the child also offered a large contribution to the variance ( $B = -3.045$ ,  $t = 1.499$ ,  $\eta^2 = .292$ ,  $p = .070$ ), as did a history of maternal mental health problems ( $B = - 2.216$ ,  $t = 1.027$ ,  $\eta^2 = .318$ ,  $p = .056$ ). These predictor variables explained large amounts of variance in maternal reported depressive symptoms, each predicting for 29-36% of the variance.

These results indicate that greater reported depressive symptoms in mothers are likely to be associated with the following: the older the child; the greater the severity of the child's feeding disorder; no presence of medical problems; tube feeding; ASD and a history of maternal mental health problems.

#### 4.5.2. Predictors of Depression in Fathers

There were five predictor variables that accounted for large amounts of variance in paternal reported depressive symptoms. The presence of behavioural and emotional reasons underlying the child's feeding disorder

offered a large and unique contribution ( $B = -2.942$ ,  $t = .386$ ,  $\eta^2 = .167$ ,  $p = .188$ ). The presence of tube feeding accounted for a significant and unique amount of variance ( $B = -7.275$ ,  $t = 2.300$ ,  $\eta^2 = .346$ ,  $p = .044$ ), as did the presence of an ASD in the child ( $B = -4.351$ ,  $t = -2.386$ ,  $\eta^2 = .363$ ,  $p = .038$ ). No history of an eating disorder in mothers also predicted large amounts of variance in paternal reported depressive symptoms ( $B = 2.595$ ,  $t = 2.077$ ,  $\eta^2 = .301$ ,  $p = .064$ ), as did a history of maternal mental health problems ( $B = -2.756$ ,  $t = -2.207$ ,  $\eta^2 = .328$ ,  $p = .052$ ).

These results indicate that presence of perceived behavioural and or emotional problems underlying the feeding disorder in the child, presence of tube feeding and ASD in the child can be associated with greater depressive symptoms in fathers. Maternal factors such as no history of eating disorders and a history of other mental health problems may also be associated with higher levels of symptoms of depression in fathers.

#### 4.5.3. Predictors of Mother and Father Anxiety

There were no predictor variables that accounted for large amounts of variance in maternal or paternal reported anxiety. It has been well established that there is a significant overlap between depression and anxiety (Kessler et al., 2008), it is therefore possible that due to the closely related nature of anxiety and depression and by implication the BDI and BAI, predictors for BAI scores may have been accounted for in the BDI scores or vice-versa.

#### 4.5.4. Predictors of Active Coping in Mothers

Child age offered a significant and unique contribution to active coping in mothers ( $B = 2.476$ ,  $t = 2.190$ ,  $\eta^2 = .459$ ,  $p = .016$ ). This indicates that the older the child was, the greater the active coping skills adopted by mothers.

#### 4.5.5. Predictors of Passive Coping in Mothers

Within the mother group, both child age ( $B = 1.069$ ,  $t = 1.032$ ,  $\eta^2 = .375$ ,  $p = .034$ ) and no presence of a medical problem underlying the feeding disorder ( $B = 27.235$ ,  $t = 2.480$ ,  $\eta^2 = .381$ ,  $p = .033$ ) accounted for large and significant amounts of variance in maternal passive coping. This indicates that the older the child and an absence of medical problems predicted higher levels of passive coping in mothers.

#### 4.5.6. Predictors of Active Coping in Fathers

There were four predictor variables that accounted for large amounts of variance in paternal active coping. These included child age, feeding disorder symptom severity, the presence of emotional or behavioural difficulties underlying the feeding disorder and absence of an ASD in the child. Child age was a significant predictor for active coping in fathers ( $B = 1.822$ ,  $t = 3.301$ ,  $\eta^2 = .521$ ,  $p = .008$ ), indicating that the older the child, the more that active coping skills were adopted by fathers. Child symptom severity offered a large amount of variance in paternal active coping ( $B = .215$ ,  $t = 1.299$ ,  $\eta^2 = .144$ ,  $p = .223$ ), meaning that the greater the severity of the feeding disorder, the more that active coping skills were adopted by fathers. Behavioural/emotional causes of the child's feeding disorder meant that greater active coping was adopted ( $B = -15.424$ ,  $t = -1.593$ ,  $\eta^2 = .167$ ,  $p = .188$ ). No presence of an ASD also accounted for a large amount of variance in paternal active coping ( $B = 14.932$ ,  $t = 1.759$ ,  $\eta^2 = .236$ ,  $p = .109$ ), meaning that absence of an ASD in the child led to more active coping in fathers.

#### 4.5.7. Predictors of Passive Coping in Fathers

Child age was the only variable that predicted for a large amount of variance in passive coping in fathers ( $B = 1.087$ ,  $t = 2.212$ ,  $\eta^2 = .329$ ,  $p = .051$ ). This indicates that as the child increases in age, the more that passive coping strategies were used by fathers.

#### 4.5.8. Predictors of Loneliness in Mothers



There were six predictor variables that accounted for large amounts of variance in maternal reported loneliness. These included child age ( $B = 2.126$ ,  $t = 1.659$ ,  $\eta^2 = .216$ ,  $p = .128$ ); no presence of an underlying medical problem in the child ( $B = 41.024$ ,  $t = 1.273$ ,  $\eta^2 = .140$ ,  $p = .232$ ); The child either currently or previously needing tube feeding ( $B = -57.786$ ,  $t = -1.692$ ,  $\eta^2 = .222$ ,  $p = .122$ ); the presence of an ASD in the child ( $B = -45.387$ ,  $t = -2.304$ ,  $\eta^2 = .347$ ,  $p = .044$ ); absence of a developmental delay ( $B = 43.961$ ,  $t = 1.970$ ,  $\eta^2 = .280$ ,  $p = .077$ ) and a history of maternal mental health problems ( $B = -20.480$ ,  $t = 1.518$ ,  $\eta^2 = .187$ ,  $p = .160$ ). These results indicate that the older the child, the greater the sense of loneliness in mothers. They also show that lack of medical difficulties and lack of developmental delay in the child predict for greater reported loneliness. The presence of an ASD in the child, previous or ongoing tube feeding and a history of maternal mental health difficulties are also associated with more loneliness in mothers.

#### 4.5.9. Predictors of Loneliness in Fathers

Four of the predictor variables accounted for large amounts of variance in father reported loneliness. The predictors included the child being tube fed ( $B = -99.574$ ,  $t = -1.977$ ,  $\eta^2 = .281$ ,  $p = .076$ ); the presence of an ASD in the child ( $B = -42.017$ ,  $t = -1.671$ ,  $\eta^2 = .218$ ,  $p = .126$ ); absence of a developmental delay ( $B = 42.017$ ,  $t = 1.277$ ,  $\eta^2 = .140$ ,  $p = .230$ ) and no history of maternal eating disorders ( $B = 29.259$ ,  $t = 1.471$ ,  $\eta^2 = .178$ ,  $p = .172$ ). It therefore indicates that fathers of children who have a history of being tube fed and a diagnosis of an ASD (and feeding disorders) are likely to report being more socially isolated than those whose children do not display these characteristics. It is of note that fathers of children with no developmental delay were more likely to experience greater loneliness than fathers of children with developmental delays. Possible reasons for these outcomes will be explored in the discussion.

#### 4.5.10. Predictors of Parent Stress in Mothers

Child age was the predictor variable that accounted for a large amount of variance in maternal reported stress ( $B = 4.307$ ,  $t = 1.970$ ,  $\eta^2 = .280$ ,  $p = .077$ ), indicating that the older the child, the greater the parental stress experienced by mothers.

#### 4.5.11. Predictors of Parenting Stress in Fathers

Child age accounted for a significant amount of variance in paternal reported parenting stress ( $B = 4.275$ ,  $t = .926$ ,  $\eta^2 = .358$ ,  $p = .040$ ) where, similarly to mothers, the older the child the greater the reported parenting stress. No history of maternal mental health difficulties accounted for large amounts of variance in father reported parenting stress ( $B = 39.912$ ,  $t = 2.096$ ,  $\eta^2 = .305$ ,  $p = .062$ ). This will be considered further in the discussion.

#### 4.5.12. Summary of Research Aim Three

**Table 4.7:** Showing predictors accounting for large amounts of variance in mothers' and fathers' responses on each of the identified variables and the amount of variance accounted for.

Independent Variable	Significant Mother Predictor Variables	Amount of Variance Explained (%)	Significant Father Predictor Variables	Amount of Variance Explained (%)
<b>Beck Depression Inventory</b>	Child Age	17.2	Behavioural/ Emotional Feeding Disorder	16.7
	Symptom Severity	15		
	No Medical Problem	17.9	Tube-Feeding	34.6*
	Tube-Feeding	36.7*	ASD	36.3*
	ASD	29.2	Maternal Mental Health Problems	32.8**
	Maternal Mental Health Problems	31.8**	Maternal Eating Disorder Problems	30.1

<b>Beck Anxiety Inventory</b>	None	None	None	None
<b>Active Coping (Brief COPE)</b>	Child Age	45.9*	Child Age	52.1*
			Symptom Severity	14.4
			Behavioural/ Emotional Feeding Disorder	20.2
			No ASD	23.6
<b>Passive Coping (Brief COPE)</b>	Child Age	37.5*	Child Age	32.9**
	No Medical Problem	38.1*		
<b>UCLA Loneliness Scale</b>	Child Age	21.6	Tube-Feeding	28.1
	No Medical Problem	14	ASD	21.8
	Tube-Feeding	22.2	No Developmental Delay	14
	ASD	34.7*	No Maternal Eating Disorders	17.8
	No Developmental Delay	28		
	Maternal Mental Health Problems	18.7		
<b>Parent Stress Index</b>	Child Age	28	Child Age	35.8*
			No Maternal Mental Health Problems	30.5**

\* Denotes significant amount of variance accounted for.

\*\* Denotes that the amount of variance accounted for by the predictor variable reached close to significance.

From the table above it can be seen that the predictor variables that most frequently impact on how parents feel include:

- The age of the child (at which they presented at a specialist feeding service). Child age accounted for large amounts of variance in maternal

reported depressive symptoms, coping, loneliness and stress. It also accounted for large amounts of variance in paternal coping and parenting stress. Therefore the older the child, the greater the experience of the identified dependent variables.

- ASD in the child, where the presence of ASD accounts for greater symptoms of depression and more reported loneliness in both mothers and fathers.
- A history of the child being tube fed accounted for large amounts of variance in parental reported symptoms of depression and loneliness.
- Absence of medical problems in the child, meaning that if there is not an underlying medical cause to the feeding disorder there are higher levels of symptoms of depression, loneliness and passive coping in mothers.
- Emotional/behavioural reasons for the feeding disorder. Where the belief that part of the cause of the feeding disorder is due to emotional or behavioural issues in the child, the more likely fathers were to report symptoms of depression and employ active coping strategies.
- The presence of maternal mental health problems is likely to predict for higher levels of reported depressive symptoms in both mothers and fathers and greater loneliness in mothers.

## **5. DISCUSSION**

### **5.1. Overview**

Until recently, feeding was conceptualised as embedded in the mother-child relationship (Chatoor et al., 1998; Coulthard & Harris, 2003). Research has indicated that maternal features, such as a history of eating disorders or difficulty in the attachment process, can lead to breakdowns in the feeding relationship which has a detrimental impact on the child's feeding throughout childhood and later life (e.g. Micali, Simanoff & Treasure, 2009; Whelan & Cooper, 2000). Fathers although relatively neglected in feeding disorder literature, have been shown to be of importance in their children's general development and wellbeing (e.g. Levy-Shiff & Israelashvili, 1988; Feldman et al., 1997). Whilst some recent literature has shown that fathers are impacted by their child's feeding disorder (e.g. Piepenstock, 2010), the understanding of the feeding relationship remains largely dyadic, with the focus on mother and child. This is reflected in the current treatment for feeding disorders, where although fathers are encouraged to attend assessment or join treatment appointments there has been little effort to expand treatment to ensure that father's experiences and needs are understood. Without this understanding it will remain difficult to treat the feeding difficulties within the wider family system, as fathers will be left out of what Minuchin (1985) describes to be a family triad of relationships, where the mother, father and child influence one another.

The central research aim was to gain a deeper understanding of how both mothers and fathers are impacted by their child's feeding disorder in order that skills and support interventions that include and are relevant for both parents can be developed and trialled. A further aim was to gain an understanding into whether different causes/aspects of the child's feeding disorder, such as a developmental delay or underlying medical problem mean that mothers and fathers are impacted differently on each of the identified variables (e.g. parenting stress, social isolation). With this knowledge, it may

be possible to develop groups where the content is relevant to both parents, and that couples facing similar experiences to one another can feel mutually supported.

The main outcomes of this study are discussed in the sections below.

#### 5.1.1. Overview of Child Factors

Of the 36 children of parents who took place in the study there was a high incidence of parental reported developmental delay amongst the child population, with 55.6% of the children having some delay. Almost 39% of the sample had a moderate to severe delay and 11.1% of the sample had a diagnosis of Autism. Parents of children with such difficulties often display higher levels of, for example, depression and parental stress (Veisson, 1999) therefore the results of this study may not only reflect the impact of having a child with a feeding disorder, but also caring for a child with additional needs.

Fifty percent of the child sample had a previous history of being tube fed and 80.6% of the children were described (by parents) to have medical problems that are believed to underlie their feeding disorder. Almost 42% of the sample were reported (by parents) to have emotional and behavioural difficulties associated with their feeding disorder. This indicates that there is a large overlap between medical, developmental and emotional behavioural aspects to feeding disorders, which is in line with the current understanding of causes of feeding disorders (Rommell et al., 2003).

#### 5.1.2. Overview of Mother Sample

The average age of mothers was 36.6 years. Twenty-five percent of mothers disclosed that they had a previous history of mental health problems and 11.1% said they have a history of eating disorders (in line with population norms). The presence of previous mental health and eating disorders in mothers has been found to be an indicator for feeding disorders in children (with an eating disorder being particularly significant) (Wheelan & Cooper, 2000). It is therefore possible that mothers with a history of difficulties themselves may be more likely to present their children at services as they

might find the experience of their child's difficulty feeding to be more stressful than other mothers.

#### 5.1.3. Overview of Father Sample

The average age of fathers was 39.5 years. Few fathers disclosed having either a history of mental health problems. It is possible that some under-reporting may have occurred within the father sample, this is in line with well founded research by Harris (2001) which notes that men are less likely to disclose mental distress unless it is severe or are under duress to do so.

#### 5.1.4. Overview of Parent Sample (joint factors)

The majority of the parent sample was married and co-habiting, with only one set of parents being separated. This is unlikely to be representative of the general population. However owing to excluding families where one parent was not involved in the child's care, this research may have been biased towards parents who are still together. This research may therefore not necessarily be representative of the feeding disorder population as a whole.

### **5.2. Discussion of Research Aim One**

The initial research aim was to gain an understanding of how mothers and fathers are impacted by five variables that were identified as being associated with having a child with a feeding disorder. These included symptoms of depression, anxiety, coping styles/skills, social isolation and parental stress. As the current research is exploratory, there was no directional hypothesis. As an initial means to gathering information on the research sample, the data was scored and the percentage of mothers and fathers that reached above clinical cut-off on each of the questionnaires was calculated.

#### 5.2.1. Depression

Seventeen percent of mothers and fathers (6 mothers and 6 fathers) scored above the cut-off score on the Beck Depression Inventory. Previous research has indicated that mothers of children with feeding disorders have significantly

higher depressive cognitions than in a control group (Golik, 2013). The incidence of depressive symptoms in mothers within this cohort is therefore in line with previous research (Ammaniti et al., 2009). There is a wide acknowledgment of the impact of maternal depression on feeding and eating disorders, where mother's mood influences how they interpret their child's feeding behaviours and their responses to their child during feeding, using more critical and intrusive language (Hellin & Waller, 1992).

Considering the incidence of father's depressive symptoms reaching above cut-off, it is surprising that only one previous study was found that has looked at and found a higher incidence of depressive symptoms in feeding disorder fathers as compared to control fathers (Gueron-Sela et al., 2011). The study mentioned also showed that paternal depression reduces father's sensitivity to their children, impacting on both day-to-day functioning and in the context of feeding. It also impacted the mother-child relationship, with mother's being less sensitive toward their children.

Acknowledging fathers' depression and its impact should be considered by clinicians, otherwise fathers could remain on the periphery of family interventions and if paternal difficulties go unnoticed, remain a maintaining factor in the child's difficulties. However, it is of note that the amount of both mothers and fathers reaching above clinical cut-off for depression is in line with the general population. Therefore it cannot be considered conclusive that parental mental health within this study is a direct reflection of the impact of the child's feeding disorder.

A significant proportion of the children in the research sample have further difficulties such as developmental delays and/or medical problems, therefore the depressive symptoms in mothers and fathers may not solely be due to their child's feeding (Veisson, 1999), and it is not possible to separate what emotions are elicited from the feeding disorder alone.



### 5.2.2. Anxiety

There was a high proportion of mothers that scored above clinical cut-off on the BAI. This is in line with previous studies that have shown heightened levels of maternal anxiety in mothers of children with feeding disorders (Chatoor et al., 1997). The high incidence of anxiety scores above cut-off in mothers has implications when developing content for skills and support groups. Anxiety can lead to more forceful feeding styles if the mother believes the child's poor feeding is due to poor parenting skills (Chatoor et al., 1997). By using such techniques it is likely that the feeding relationship breaks down further and the child's problems worsen. A study by Gueron-Sela et al (2011) argued that maternal anxiety and constant surveillance of the child's eating and weight gain must be addressed.

No previous studies were found that address the father's anxiety in the context of feeding disorders. This study found that 8% of the fathers reached above cut-off on the BAI. There was no control group to show whether this incidence would be comparable to the non-feeding disordered population, therefore one must be careful in drawing any conclusions about whether fathers of children with feeding disorders are at greater risk than the 'normal' population. However it must be noted that there are some fathers that are significantly impacted, therefore it may be an issue worth considering when developing content for groups. It can be hypothesised that mother's experience greater anxiety in relation to their child's feeding disorder than fathers, as they are more likely to be present at mealtimes. Perhaps by being at work more frequently, fathers might experience a reduction in their anxiety, whereas mothers are more frequently the parent responsible for feeding, having greater exposure to stressful mealtimes (Gueron-Sela et al., 2011).

### 5.2.3. Coping

The results of this study indicate that more mothers reached the cut-off for both active and passive coping strategies than fathers. As mothers are more likely to be involved in feeding their children, they possibly need to develop a greater range of coping strategies in order to manage the day-to-day challenges of caring for and feeding their child (Brehm, Kassin & Fein, 2004).

On the other hand, it may be that mothers have greater access to support systems or are more willing to ask for/seek out help, meaning that they are better able to develop coping strategies, whereas fathers do not have the same support systems around them and may be less likely to seek support. For example, there are more support groups in the community designed for women. Fathers may need greater encouragement to seek out support, and the available treatment programs need to be relevant and accessible to fathers as well as mothers. Greater clinical support can offer coping strategies that reduce maladaptive behaviours such as force-feeding or shouting at their child during meals (Raina et al., 2004).

It is of note that more mothers reached significance for passive coping (i.e. blaming themselves or denying what is going on), this again may be due to the greater proximity to their child's difficulties than fathers, however it is an issue that needs to be addressed when developing skills and support groups.

#### 5.2.4. Social Isolation

There were high numbers of both mothers (38%) and fathers (30%) that displayed scores above cut-off on the UCLA loneliness scale. The incidence of loneliness in mothers is in keeping with previous research that has shown that mothers of children with feeding disorders often have poor social networks and limited support from both their immediate and wider family (Sanders et al., 1993). Farrow and Blissett (2006) found that mothers of children with feeding disorders often described themselves as feeling very isolated and expressed low self-efficacy, leading to further withdrawal from friends and family.

The incidence of paternal loneliness and social isolation was almost as high as that of mothers. Whilst there was no control group within this study and the sample size was relatively small, it seems to be an important finding, as no previous research was found regarding fathers of children with feeding disorders experiencing significant loneliness and social isolation. Starting a dialogue about feelings of isolation may enable mothers and fathers to appreciate that the other parent may share similar experiences. It is possible

that both parents think they are alone in how they are feeling and have not had the opportunity to listen to one another. This may enable parents to feel less isolated and begin to support one another, whether emotionally or with the practical aspects of feeding/childcare. Support groups where both parents are included may also go some way in showing parents that they are not alone in the difficulties associated with parenting a child with feeding disorders. It is also of note that there are close links between social isolation and depression, in particular the lack of a confidante (Brown & Harris, 1978) and that by addressing the issue of access to social support and support from within the parental relationship, may also impact positively on depressive symptoms (Teo et al., 2013).

#### 5.2.5. Parent Stress

There were a greater number of mothers 13 (36%) than fathers 8 (22%) who scored in the 90<sup>th</sup> percentile or above for total parenting stress. The proportion of mothers and fathers experiencing high levels of parenting stress is in line with previous research by Piepenstock (2010), where although mothers' scores were overall higher, fathers of children with feeding disorders had higher scores than matched controls. Research into childhood chronic illness has shown that both parents experience increased stress (i.e. Auslander, Netzer & Arad, 2003) and it is possible that this research highlights that feeding disorders can be categorised similarly. If paternal stress is not addressed alongside maternal stress, mealtime interactions where the father is present may be detrimental to the feeding relationship.

#### 5.2.6. Summary of Research Aim One

Looking at how both parents score on the five variables, it is clear that although more mothers reach cut-off on each of the variables (except for depression, which is equal), there are a number of fathers that are significantly impacted. It is important that in the development of skills and support groups, fathers' experiences are considered alongside those of mothers. By having this information, both members of the parent couple can be made aware that research has shown both parties to be affected; thereby

possibly enabling a dialogue to begin between parent-couples to better support one another and their child.

### **5.3. Discussion of Research Aim Two**

The second research aim was to gather further information on the overall differences between mother and father scores on each of the five variables. Due to the exploratory nature of the study, there were no directional hypotheses.

Following a series of Wilcoxon Rank tests, mothers were found to have significantly higher scores on each of the scales including; depression, anxiety, coping, loneliness and parent stress. These outcomes highlight that although there are a number of fathers who reach above cut-off on each of the variables (as noted above) mothers score more highly overall. It can be hypothesised that this is due in part to mothers more often being the primary carer and therefore are more frequently present at stressful mealtimes and are perhaps more acutely aware of the nutritional intake of the child or lack there-of. It would have been useful to know which of the parents take the role as primary carer, however previous research on a similar cohort has shown that the majority of the childcare (more specifically mealtimes) is left to the mother (Piepenstock, 2010). These findings support previous research for parent depression and stress, where maternal scores have been found to be significantly higher than those of fathers (Golik et al., 2011; Piepenstock, 2010). The studies by Golik et al (2011) and Piepenstock (2010) found that paternal depression and stress scores were significantly higher than controls, indicating that these factors are pertinent to the father feeding disorder population.

No previous research was found that looked at fathers' anxiety, coping style and social isolation within the feeding disorder literature, therefore the current findings regarding paternal responses to these variables are to the best of the researcher's knowledge, novel. Literature focussing on parents of children with chronic illness suggests that both parents often exhibit higher anxiety,

develop avoidant coping mechanisms and can feel extremely isolated owing to the level of medical intervention or greater level of care needed by their children (Smith & Kaye, 2012). A study on parents of children with Cystic Fibrosis found that across a sample of mothers and fathers 51% of mothers and 44% of fathers showed elevated anxiety scores (Quittner et al., 2010), and even though mothers' scores were overall higher, a high proportion of fathers were affected. Whilst feeding disorders do not have quite the same level of ongoing medical care, there are daily concerns regarding the child's health and ongoing battles over food, and although fathers may be removed from the day-to-day struggles of having a child with feeding disorders, they are unlikely to be immune to the overall impact. The findings that fathers' scores are lower overall, may indicate that mothers do not receive enough respite or support in managing a child with a feeding disorder, and perhaps fathers have a greater role to play in the management of the difficulties within the family system. This information highlights that fathers might be in a position of greater emotional strength and, with the correct support, be encouraged to become a more active member of both the treatment process and general family life. The greater inclusion of fathers must be considered carefully, as it is important that fathers do not feel blamed for being less impacted by their child's difficulties but by being less affected they might offer potential solutions.

#### **5.4. Discussion of Research Aim Three**

The final research aim was to explore whether the focus of parent interventions may need to differ according to characteristics of the child's presentation, for example: age, broad type of feeding problem (medical/non-medical; ASD/no ASD; tube fed/ no tube), and severity of feeding. This was explored using a Multivariate General Linear Model, where the dependent variables were the five identified areas of concern for parents of children with feeding disorders (depression, anxiety, coping, loneliness and stress) and the predictor variables were mainly child characteristics as mentioned above. Mother and father variables were loaded in to two separate GLM's with all the

predictor variables. This ensured that the unique contribution of each of the predictor variables on each of the dependent variables was shown.

As there were no predictors that accounted for large amounts of variance in either maternal or paternal anxiety, it was not clear which factors impacted parental anxiety. Due to the overlap between outcomes on the BAI and BDI, predictors for parental anxiety might be accounted for in predictors for parental symptoms of depression and vice-versa (Kessler et al., 2008). Each of the dependent variables will be discussed below.

#### **5.4.1. Predictors for Mother and Father Scores across the Five Variables**

##### *5.4.1.1. Depression (mothers)*

The outcome of the mother participants GLM showed that six predictor variables offered unique and large amounts of variance in maternal reported symptoms of depression. These included; child age, symptom severity, no presence of a medical problem in the child, a history of tube feeding, ASD and a history of maternal mental health problems.

With increasing age and with greater severity of feeding disorder symptoms more depressive symptoms were reported. Younger children are often expected to be fussy or difficult feeders but as children get older feeding should become a more independent act (Ramsay, 2013). The gap between a child with feeding disorders and their peers may widen and parents may be more likely spend to a disproportionate amount of time preparing meals and encouraging feeding. The impact of the severity of the feeding disorder may increase parents' feelings of helplessness and hopelessness about the situation, thereby increasing symptoms of depression.

The presence of an ASD, tube-feeding and an absence of medical problems also appear to be associated with maternal depression. Previous research highlights the difficulty in managing the emotional, physical and behavioural demands of having a child with Autism, leading to parents feeling very isolated (Dunst et al., 1990). Research has shown that clinicians often feel de-

skilled when supporting a family where the child has an ASD and feeding difficulties, leaving parents feeling increasingly alone (Rogers, Magill-Evans & Rempel, 2012). Veisson (1999) highlights that parents of children with significant additional needs, such as Autism, often experience greater symptoms of depression. The outcome of the present study would therefore be in line with previous research.

The absence of medical problems is associated with depressive symptoms in mothers. A possible explanation is decreased service involvement resulting in less support. It is possible that where there is a medical problem underlying the feeding disorder, there is hope that there could be a concrete medical solution, whereas if the feeding disorder is understood to be emotional/behavioural, there is less likely to be a straightforward solution, perhaps eliciting feelings of hopelessness. On the other hand, the child having a history of being tube-fed was associated with depression in mothers, and this would have involved a degree of medical intervention. Tube-feeding does not link the root of the feeding disorder to medical issues per-se, but may speak of the severity of the disorder and the level of parental intervention needed to ensure the child's physical health.

Previous history of mental health problems in mothers is also likely to have some impact, this is logical as it is likely the individual will be more vulnerable to feeling low when under stress and may have ongoing difficulties that were picked up on the BDI.

#### *5.4.1.2. Depression (fathers)*

Paternal depressive symptoms were associated with parental understanding of their child's feeding disorder being behavioural or emotional in origin, tube-feeding, ASD and maternal mental health or eating difficulties. It is possible where there is a medical problem, a solution seems possible, whereas if emotional/behavioural in origin, there is no clear resolution to the feeding disorder. It may cause fathers to feel more helpless with regards to supporting their child, they may also see the child as unwilling to change. It is also possible that the child's feeding difficulties are an emotional response to

stressors within the home environment, such as a parent being unable to contain their or the child's emotions, leaving the child feeling 'insecure' (both during and away from feeding) (Chatoor & Egan, 1983). In such cases it is possible there is either very high or low 'expressed emotion' within the family setting, which may impact all members of the family, and in this instance, possibly paternal mood (Hatfield et al., 1997).

The presence of tube-feeding and ASD in the child is likely to have an impact on fathers in a similar way to mothers, with ongoing stress and the greater need for ongoing physical attention that is likely to have an impact day-to-day family functioning. It is likely that fathers as with mothers will have to shape their lives around the additional care needed for their child and may leave little time or energy to process the impact on parental mental health.

The mental health history of the mother has a significant impact on fathers' symptoms of depression. It is possible that due to maternal mental health or eating disorders there is little space for fathers to discuss how they are feeling. They may carry the responsibility of caring for both mother and child without emotional support externally or from within the family unit.

#### *5.4.1.3. Coping (mothers)*

The sole significant predictor for maternal active coping was the age of the child, with an increase in age indicating greater levels of active coping. The majority of the mothers reached above cut-off for active coping, suggesting that they generally develop a range of positive skills and their ability to develop and use these skills increases with the age of their child. It is possible that as mothers are more often the primary carer of the child, they need to find a way of managing and they may also make more use of external sources of support, such as GPs, health visitors as well as family and friends.

Another possibility is that as their child gets older there are more demands to deal with. The child may have had their feeding disorder for longer and mothers would need a support or belief system in place in order to face the continuing difficulties.



The extent of passive coping in mothers was significantly associated with child age and absence of a medical problem underlying the child's feeding disorder. The link between age of child and passive coping is likely to be similar to active coping, as there will be a greater need to find ways to manage as the child gets older. Absence of medical problems in the child lead to greater passive coping, suggesting that the less medical intervention needed, the fewer agencies available for support, therefore mothers might employ less 'positive' coping strategies. Although passive coping was overall less prevalent than active coping it is something that needs to be considered in the development of skills and support groups.

#### *5.4.1.4. Coping (fathers)*

Greater active coping in fathers was significantly predicted by the age of the child, symptom severity, the presence of emotional or behavioural feeding disorder and no ASD in the child. The older the child the more fathers engaged in both active and passive coping, perhaps as there is more time for the development of coping strategies whether positive or negative in nature. When developing treatments it should be considered that what is relevant to parents of a school age child may be very different to parents with an infant or toddler.

The severity of the feeding disorder also indicated more active coping in fathers, indicating the need to develop coping strategies. Parental understanding that the feeding disorder is caused by emotional or behavioural difficulties within the child/family, also appeared to lead to greater active coping in fathers, perhaps if fathers believe there is an element of the child being able to 'control' their feeding, they learn to find a means of coping with the situation as it might seem difficult to change.

#### *5.4.1.5. Loneliness (mothers)*

Having a child with Autism but without underlying medical concerns significantly predicted maternal loneliness and isolation. This is in line with previous research describing clinical services as often withdrawing from

treating a child with Autism inferring that the challenging behaviour (in this case feeding) is so ingrained to the ASD that treatment is unlikely to help (Twachtman-Reilly et al, 2008). Whilst this may or may not be the case for all services, it is likely to leave these mothers feeling unsupported and isolated. The present study also supports research highlighting how isolating it can be for parents (particularly mothers) not able to access or make use of public amenities e.g. playgroups or have difficulty meeting with friends when their child requires greater support (Andrew & Sullivan, 2010). Staying at home may provide a stable routine but mothers may then feel isolated.

Absence of medical issues in the child also predicted greater loneliness in mothers, again possibly because families have less input from medical services, therefore less support from wider systems and less opportunity to meet families who have children with similar difficulties. When developing a support group this should be taken in to consideration, as without ongoing clinical support and access to other families facing similar situations, families are likely to be more isolated than those who have other sources of support.

The experience of having a tube-fed child also seems to cause a greater sense of loneliness and isolation in mothers. Previous studies note that parents find administering feeds via a gastrostomy or naso-gastric tube to be 'unnatural' and singles their child out as different, perhaps leading to the judgement of others (Peterson et al., 2007). Mothers may therefore feel that they need to exclude themselves from social situations where their child would need to be fed. There may also be a lack of understanding from other children or parents and mothers may therefore not wish to place themselves or their child in situations where others may comment upon how their child is fed.

As with many of the other emotions elicited by having a child with a feeding disorder, child age appears to have an impact on the loneliness experienced by mothers. As children get older there is often less of a network for parents and whilst it is common for babies and toddlers to be fussy eaters, it becomes less 'socially acceptable' as the child gets older, thereby not having other

people who are able to understand or offer the necessary support.

Maternal mental health difficulties also predicted maternal loneliness. It is likely that these experiences go hand in hand, and the mothers who have a history of mental health problems may find it harder to actively seek support, thereby finding their child's difficulties increasingly isolating.

#### *5.4.1.6. Loneliness (fathers)*

Similarly to mothers, the presence of ASD and tube feeding predicted large amounts of variance in paternal loneliness. Both autism and tube-feeding have a significant impact on the family who find it difficult to take part in day-to-day activities due to lack of facilities for people with developmental delays or differing physical need. Both Autism Spectrum Disorder and tube-fed children have external behavioural and physical features which parents may find more isolating than issues such as the severity of the feeding disorder (without tube-feeding) as this can be managed to some extent in private at prescribed times of day.

#### *5.4.1.7. Parent Stress (Mothers and Fathers)*

Parent stress in both mothers and fathers was predicted by both the age and presence of a developmental delay in their child. It is likely that the older the child, the longer the feeding difficulties have been present, thereby causing greater stress in parents. It is possible that the behaviours surrounding feeding also become increasingly stressful as the child gets older as they may be better able to express their anger and frustration or physically leave the table. Again this highlights the difference in the challenges faced by parents of older and younger children and should be considered when developing support groups. Father stress was also predicted for by absence of maternal mental health difficulties. A possible explanation is that mothers without a history of mental health difficulties have less access to external clinical support and therefore rely on their partners for greater emotional support; this in turn may make the experience of parenting more stressful for fathers. This finding appears to be in opposition to the above outcome that highlights the presence of mental health difficulties in mothers predicts for greater

depressive symptoms in fathers. Whilst there is likely to be some correlation between parental stress and depression, it must be considered that parental stress can occur outside of depressive symptoms, and therefore might be predicted for by different factors.

#### 5.4.2. Summary of Research Aim Three

Child age was a significant predictor of greater overall emotional distress in parents. Parents of infants and toddlers will be facing different issues to those of school age children and may need support groups tailored accordingly. The presence of an Autism Spectrum Disorder in the child also seemed to have a profound effect on both parents, therefore the differing experience of families where the feeding disorder is accompanied or caused by developmental issues must be considered when developing groups. It is likely that these families are already addressing a number of complex behavioural and emotional needs, and may therefore need support tailored to understanding that the difficulties surrounding feeding are a part of a significantly more complex picture. Absence of medical problems in the child led to greater isolation in parents, therefore the access to ongoing support systems must be taken into account when developing groups, as it is likely that families where the child is supported medically will have ongoing support systems in place. Overall, it does appear that different child characteristics, elicit different emotional responses from both mothers and fathers. Generalised skills and support groups may not address parental need adequately.

### **5.5. Limitations**

#### 5.5.1. Measures

A limitation of the study is that issues not covered by the questionnaires could not be explored. For example it could not be measured if parent stress was related to loss of income if mothers were unable to work owing to feeling unable to leave their child in the care of others. A focus group in addition to the questionnaires may have been able to address this limitation. It was hoped that focus groups would make up a part of the current research, however it was not possible to find enough parent couples to attend a focus

group due to the amount of time needing to be taken off work, or the amount of travelling that would be incurred. The researcher is hopeful that when a skills and support group is piloted, parents can be asked for feedback about other issues that should be taken in to account. It may also need to take another form, such as via an internet forum or individual interviews, if parents struggle to attend group meetings.

Although the participants were asked to fill out the questionnaires in relation to their child's feeding disorder, it is difficult for parents to distinguish which of their feelings were directly linked to this as opposed to other issues, either with the child or more generally. A specific example of this is the overlap between developmental delays, medical problems and feeding disorders. The results have to be interpreted with caution, as it is unclear how much of the responding relates to the feeding alone. However due to the significant overlap of medical and developmental difficulties with feeding disorders, it may not be possible to distinguish which aspect elicits particular responses in parents. Parental report of feeding disorder, developmental delay and underlying medical disorder were relied upon within this study, rather than clinical diagnosis per-se. Therefore one must consider that parental perception can be skewed by anxiety surrounding the problem. A recent study by Harvey et al (2013) found that parental anxiety was an independent predictor for whether the parental report of the severity of their child's feeding disorder, matched the child's actual food intake. One must therefore consider possible parental anxiety as a factor when interpreting this study, as the child's problem might be perceived as more severe, where there is greater parental anxiety.

There were limitations to using the Brief COPE as there was no recommended scoring procedure or means of defining different coping styles. It was left to the researcher to define the terms of active and passive coping. There was also no recommended cut-off score, which also had to be defined by the researcher. This meant that the scoring used in this study for the Brief COPE has not been replicated elsewhere and must therefore be interpreted with caution. It is also possible that there were higher levels of 'socially

acceptable' responding as for example parents may not wish to disclose if they turn to alcohol to help them to cope due to the attached stigma.

The demographic questionnaire required parents to state their understanding of the origins of their child's feeding disorder but many parents ticked more than one reason, therefore although 'type of feeding disorder' has been placed into different categories for the current study, one must be aware that there is significant overlap across each of the categories.

Within this study it was decided to focus on effect sizes of parent and child factors on the variables, whilst this is now a commonly used strategy for looking at the amount of impact a predictor variable has on independent variables, it does not offer information on whether the outcome reaches a particular level of significance. The results must therefore be understood with caution as they do not offer information on how likely the results are to be replicated in further studies.

#### 5.5.2. Sampling Procedure

A limitation of the study was that the measures were often given to one parent attending the appointment. Therefore the other parent did not receive a verbal explanation of the way in which the questionnaires were to be answered and the confidentiality of the study. Whilst everything was covered in the information sheet, it did not allow for a face-to-face dialogue regarding the study. This may have impacted on how the participant understood the study and the way the questionnaires were answered. Given the sensitive nature of the study, non-attending parents may have felt uncomfortable contacting the researcher (even though contact details were given) to ask questions if they had any concerns leading to a lower response to the questionnaires. Parents who did not attend may also have spent less time filling out the questionnaires as they may be doing so at the request of their partner rather than as a choice made by both parents together.

Only 50% of the questionnaire packs were returned by both parents, whereas a previous study within the same service had a 90% return rate (Piepenstock, 2010). It is possible that as the current study involved disclosing feelings such as depression and loneliness, parents were less inclined to take part. The previous study by Piepenstock (2010) placed a greater emphasis on parental relationship, rather than disclosing information specifically relating to emotional wellbeing. Whilst there were 36 parent couples recruited, this remains a relatively small sample size and results must be understood with caution.

As it was not possible for the researcher to meet with all the parents individually, some parents were contacted by telephone and packs were sent out in the post. Possibly lack of face-to-face contact with the researcher resulted in parents being less inclined to take part.

The ability for parents to attend must also be considered when trying to establish parent groups within a national service, as it may not be possible to coincide parent groups alongside individual treatment and parents might be reluctant to take significant time out of work. It is possible that the development of parent groups would be more plausible within local feeding services. The use of internet forums could also be considered in order that parents are able to access support (guided by a clinician) without it significantly impacting work or childcare. It must also be noted that the findings from this study are from a Tier 4 feeding service and the presentation of the children is likely to be more severe than Tier 2/3 services and may therefore not be as representative of families attending local services.

Owing to the aim of this study being a comparison between mother and father parent couples on a range of variables, both same-sex parents and single parents were excluded, the results will therefore not be representative of all parents with children with feeding disorders.

A further limitation of the study is that although the children have been considered as having 'feeding disorders' for the purpose of this study, the

majority of children attending the Tier 4 feeding disorder service do not actually meet the DSM-IV criterion for feeding disorders, as weight is usually maintained to a degree, often due to food supplements or tube-feeding (Bryant-Waugh et al., 2010). The DSM-V acknowledges that most children within specialist feeding services fell short of meeting DSM-IV diagnosis, and has widened the diagnostic criterion to include weight maintenance through non-typical feeding processes such as eating a highly selective or pureed diet, high calorie drinks or enteral feeding (Bryant-Waugh et al., 2010). The current study uses clinical diagnosis rather than DSM-IV criteria. If all the children had to fulfil DSM-IV criteria it is likely there would not have been enough people eligible to take part in the study.

## **5.6. Implications**

### 5.6.1. Clinical Implications

An important clinical implication of this study is that services offering treatment to families of children with feeding disorders must be aware that although overall there appears to be greater impact on mothers in regard to depression, anxiety, loneliness and stress, fathers are by no means unscathed e.g. as many fathers as mothers reached above clinical cut-off on the Beck Depression Inventory. This implies that whilst the majority of fathers have significantly less symptoms of depression than matched mothers, clinicians need to be aware that some fathers will be heavily impacted and should be vigilant regarding fathers' mental health as well as mothers.

It is interesting that on the demographic questionnaire, very few fathers responded that they had/have mental health difficulties. This may indicate that father's under-report the emotional impact of having a child with feeding disorders (this is in-keeping with previous research indicating that men frequently under-report mental illness unless in crisis (Harris, 2001)). Whilst it may not be possible to ask all parents to complete a depression scale prior to the commencement of their child's treatment, if parent skills and support groups are piloted, this would be a useful piece of information and may offer



the opportunity for parents to seek help elsewhere if the symptoms are generalised beyond the child's feeding disorder.

Depression, anxiety and loneliness in mothers appeared to be significantly mediated by absence of medical problems in the child. Perhaps it should be routine to make parents aware of and encouraged attend, local parent support groups, as the treatment for the child's feeding disorder is likely to be time limited and families may lose clinical support following the end of treatment.

As mentioned above, a number of fathers (as well as mothers) scored above cut-off for depression, anxiety and loneliness on the questionnaires, whilst this is in line with the general population, the family system may be more constructive and cohesive in addressing the child's difficulties if parental issues are addressed as routine. If symptoms are ignored in either parent, the cycle of negative mealtimes or a stressful home environment will likely continue and the child's feeding disorder will be harder to treat.

#### 5.6.2. Future Research

The current study has highlighted that a number of mothers and fathers are impacted by their child's feeding disorder on a range of variables including symptoms of depression, anxiety, loneliness and parent stress. One previous study in the feeding disorder literature used both a clinical and control group to show differences in outcomes on parent stress (both mothers and fathers) (Piepenstock, 2010). This study indicated that although mothers were significantly more stressed than fathers, both parents were significantly more stressed than controls. Future research could gather data from a matched control group (as far as is possible) using the same outcome measures to illuminate whether significantly more mothers and fathers of feeding disordered children reach above cut-off than parents of healthy children and whether overall scores were higher in mothers and fathers of the feeding disorder population. This would go further in helping to understand the impact of feeding disorders on fathers as well as mothers.

Much of the previous research on the treatment of feeding disorders has investigated the mother-child relationship and the impact on the mother, therefore the identified variables used in this research was based on maternal experience. It is possible that there are other issues impacting fathers that have not been covered in previous literature, therefore a more qualitative approach could be useful in establishing what difficulties are experienced by fathers in relation to their child's feeding. It would therefore be useful for future research to encompass focus groups that enable both parents to discuss other issues that are pertinent to both parents. Parent interviews or internet-based focus groups should also be considered as a means of qualitative data collection.

The current study was exploratory and was aimed at gathering information to develop content for a 'skills and support group'. Future research could use the information to help pilot a support group that is relevant to both mothers and fathers of children with feeding disorders. Specifically parents could be made aware of the impact of having a child with feeding disorders on parental mental health and that fathers can be significantly impacted as well as mothers. The key issues derived from this study are the presence of depressive symptoms in both parents, the level of isolation felt by both fathers as well as mothers and the impact of both child age and the presence of developmental delay and child age on parents.

Future research might include trialling groups split according to the age of the child and/or the presence of and Autism Spectrum Disorder / developmental delay to increase relevant support. Future research could also compare outcomes on each of the parent variables and child symptoms in families where parents have and have not attended skills and support groups.

This research highlights the systemic nature of feeding disorders and the emotional impact on both parents. Many of the children in the study have siblings and it is not clear how they are affected by having a member of the family with a feeding disorder. Future research might aim to include the whole

family system and find out how each member is impacted and the role they could play in the treatment process.

## **5.7. Summary/Conclusions**

The aim of the current research was to establish how both mothers and fathers are impacted by having a child with feeding disorders across five previously identified variables including, depression, anxiety, coping skills, loneliness and parent stress, in order to help with the development of content for 'skills and support' groups that are relevant to both parents. A further aim was to explore whether child characteristics (such as developmental delay, medical problems or age of child) impact parents differently. This information could be used to create groups that are designed specifically for the needs of parents. Although there has been a recent increase in the inclusion of fathers within the feeding disorder literature, it remains relatively limited and mothers continue to be the main focus, this research goes a little way to addressing the gap.

The research sample consisted of 36 pairs of parents who have children attending a Tier 4 feeding disorder service. The children were aged 0-8years and were considered to meet clinical and/or diagnostic criteria for a feeding disorder. Matched mothers and fathers were asked to complete a series of five questionnaires and fill out demographic information about their child and themselves.

Whilst the questionnaires were not used as diagnostic tools, six mothers and six fathers scored above clinical cut-off on the BDI, indicating that a high percentage of mothers and fathers are significantly impacted by their child's feeding disorder indicating that parental mental health should be considered as a priority within treatment programs. This study also highlights the relational aspect of feeding disorders and it is possible that the child's difficulties will be maintained if the needs of all family members are not addressed. A number of mothers and fathers also scored highly on each of the identified variables such as parenting stress and loneliness. Whilst many

studies have identified mothers as being impacted on each of these variables, fathers have been largely omitted from studies. As with previous studies mothers' scores were higher overall than fathers, yet fathers were impacted to varying extents across each of the variables. Much of the information gathered by this study is novel and should be disseminated to ensure that fathers are included in treatment. This will enable clinicians to identify whether fathers (as well as mothers) need to be referred for further psychological support.

This study went further in identifying whether the focus of interventions should differ according to the presentation of the child. For example: child age, whether the child has a developmental delay/Autism, severe medical issues and the severity of the feeding disorder. It was found that child age significantly impacted emotional distress in parents, with parents of older children displaying greater distress. It would therefore be useful to tailor interventions according to the age bracket of the presenting child. The results also indicated presence of an ASD or developmental delay in the child impacted parents differently to those without, as did absence of medical difficulties, as families felt more isolated. Skills and support groups may therefore benefit from being designed according to child presentation.

This study has limitations, including the difficulty in distinguishing which of the emotions elicited by parents were related directly to the feeding disorder as opposed to other issues surrounding the child or family life. A further limitation was that the questionnaires chosen by the researcher related to previous research rather than direct accounts from parents. A qualitative element to the study may therefore have revealed other issues pertinent to parents. However there are a number of useful implications that can be extrapolated from the study. It was of particular note that fathers of children with feeding disorders often feel isolated, and owing to mothers being targeted for intervention, have few sources of support. Whilst group interventions can be tailored to include paternal needs, it is perhaps necessary to think beyond the physical attendance of therapeutic intervention, towards internet-based skills and

support groups that offer fathers (and mothers) access to therapeutic support without having to take significant time out of work.

If a skills and support group is developed following this study it is hoped that clinicians will take note of the key outcomes of this study. Particular emphasis should be placed on ensuring the mental health needs of both parents are considered and further support offered if necessary; for example a BDI and a BAI could be administered prior to the group commencing. It would be important that the clinician normalises the sense of isolation and stress experienced by both parents, with particular emphasis on paternal isolation, as access to local support is often geared toward mothers as the primary carer. By enabling a dialogue within and between families, it is hoped that a supportive and dynamic setting will be created to support parents in treating the child's feeding disorder. It should be considered that fathers might need more support in the development of coping strategies and perhaps need encouragement to disclose how they are feeling. Clinicians should also consider tailoring the groups according to the age of the child, presence of underlying medical issues and diagnosis of ASD/developmental delay, as these appear to have an impact on parental experience and the amount of external support offered.

Using the information gathered from this study it is hoped that future interventions will be more meaningful and useful to both parents and that the inclusion of fathers leads to all family members feeling more supported and might enable a shift in the family system and impact positively on the outcome of the child's treatment.

## 6. REFERENCES

- Abidin, R. R. (1990). *Parenting Stress Index (Short form): Test manual*. Charlottesville, VA: Pediatric Psychology Press.
- Abidin, R. R. (1995). *Parenting Stress Index* (3<sup>rd</sup> ed.). Odessa, FL: Psychological Assessment Resources.
- American Psychiatric Association (1994), *Diagnostic and Statistical Manual of Mental Disorders* (4th ed). Washington, DC: American Psychiatric Association.
- Ammaniti, M., Lucarelli, L., Cimino, S., D'Olimpio, F., Chatoor, I. (2009). Maternal Psychopathology and Child Risk Factors in Infantile Anorexia. *International Journal of Eating Disorders*, 43(3): 233-240.
- Ammaniti, M., Lucarelli, L., Cimino S., D'Olimpio, F., Chatoor, I. (2011). Feeding Disorders of Infancy: A Longitudinal Study to Middle Childhood. *International Journal of Eating Disorders*, 45(2): 272-80.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Arlington, VA: American Psychiatric Publishing.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Andrew, M.J. & Sullivan, P.B. (2010). Feeding difficulties in disabled children. *Paediatrics and Child Health* , 20 (7), 321-326.
- Atzaba-Poria, N., Meiri, G., Millikovsky, M., Barkai, A., Dunaevsky-Idan, M. and Yerushalmi, B. (2010), Father–child and mother–child interaction in

families with a child feeding disorder: The role of paternal involvement. *Infant Mental Health Journal*, 31: 682–698.

- Atztaba-Poria, N., Meiri, G., Yerushalmi, B. (2012). Infant feeding and sleeping disorders: Psychiatric diagnostic classification and parent-child interaction patterns. Published for the Ministry of Health, Chief Scientist Office Jerusalem.
- Auslander, G., Netzer, D. & Arad, I. (2003). Parental anxiety following discharge of their very low birthweight infants. *Family Relations*. 52: 12-21.
- Bader, A.P. & Phillips, R.D. (1999). Fathers' proficiency at recognizing their newborns by tactile cues. *Infant Behaviour and Development*, 22: 405-409.
- Barker, C., Pistrang, N., & Elliott, R. (2002). Research methods in clinical psychology: An introduction for students and practitioners (2<sup>nd</sup> ed.).
- Beck, A. T., & Steer, R. A. (1990). *Manual for the Beck Anxiety Inventory*. San Antonio, TX: Psychological Corporation.
- Beck, A.T., Steer, R.A & Brown, G. K. (1996). *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation.
- Belsky, J., Rovine, M. & Fish, M. (1989). The developing family system. *Minnesota Symposia on Child Psychology*, 22, 119-166.
- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships*, 12, 463-472.
- Blissett, J. & Harris, G. (2002). A behavioural intervention in a child with feeding problems. *Journal of Human Nutrition and Dietetics*, 4: 255-60.
- Blissett, J., Harris, G. & Kirk, J. (2001). Feeding problems in Silver-Russell syndrome. *Developmental Medicine and Child Neurology*, 43, 39-44.

- Blissett, J, Meyer, C, Haycraft, E. (2006). Maternal and Paternal controlling feeding practices with male and female children, *Appetite*, 47: 212-219.
- Bowlby, J. (1969). Attachment and loss, vol. 1: attachment. London: Hogarth Press.
- Bowlby J (1988) "A Secure Base: Clinical Applications of Attachment Theory". Routledge. London.
- Braun, M. J. & Palmer, M.M. (1986). A Pilot Study of Oral-Motor Dysfunction in "At-Risk" Infants. *Physical & Occupational Therapy in Pediatrics*. 5: 13–25.
- Brehm, S. (2004). Social Psychology. Houghton Mifflin Harcourt. London.
- Brinker, R., Seifer, R., & Sameroff, A. (1994). Relations among maternal stress, cognitive development, and early intervention in middle--and low-SES infants with developmental disabilities. *American Journal on Mental Retardation*, 98, 463-480.
- Brown, G. W., & Harris, T. (Eds.). (1978). *Social origins of depression: A study of psychiatric disorder in women*. London: Routledge.
- Bryant-Waugh, R. (2013). Avoidant restrictive food intake disorder: An illustrative case example. *International Journal of Eating Disorders*, 46: 420-423.
- Bryant-Waugh., R., Markham, L., Kreipe, R.E. & Walsh, B.T. (2010). Feeding and eating disorders in childhood. *International Journal of Eating Disorders*, 43(2), 98 - 111.
- Bryant-Waugh, R. Turner, H., Jones, C. J. & Gamble, C. (2007). Developing a skills and support intervention for mothers with eating disorders: Part II.



- Piloting a group intervention. *European Eating Disorder Review*, 15, 439-448.
- Bryant-Waugh, R.J. & Piepenstock, E.H.C. (2008). Childhood disorders: Feeding and related disorders of infancy or early childhood. In A. Tasman, J. Kay, J. A. Lieberman, M. B. First & M. Maj. (Eds.), *Psychiatry* (Third Ed.). New York: Wiley and Sons.
- Burklow, K. A., Phelps, A. N., Schultz, J. R., McConnell, K. & Rudolph, C. (1998). Classifying complex pediatric feeding disorders. *Journal of Pediatric Gastroenterology and Nutrition*, 27: 143–147.
- Carver, C., Scheier, M. & Weintraub, J. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-83.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4: 92-100.
- Chatoor, I. (1997). Feeding and other disorders in infancy. In A. Tasman, J. Kay, & J. Lieberman (Eds.), *Psychiatry* (pp. 683-701). Philadelphia: W.B. Saunders.
- Chatoor, I. (2000). Feeding and eating disorders of infancy and early childhood. In: H, I, Kaplan, B.J. Sadock (Eds), *Comprehensive Textbook of Psychiatry, Vol. VII*, (pp. 2704-2710).
- Chatoor, I. (1989). Infantile anorexia nervosa: A developmental disorder of separation and individuation. *Journal of American Academy of Psychoanalysis*, 17(1), 43-64.
- Chatoor, I., & Egan, J. (1983). Nonorganic failure to thrive and dwarfism due to food refusal: A separation disorder. *Journal of the American Academy of Child Psychiatry*, 22, 294 – 301.

- Chatoor, I., Egan, J., Getson, P., Menvielle, E., & O'Donnell, R. (1988).  
Mother-infant interactions in infantile anorexia nervosa. *Journal of the American Academy of Child and Adolescent Psychiatry*, 27, 535 – 540.
- Chatoor, I., Ganiban, J., Harrison, J., Hirsch, R. (2001). Observation of  
feeding in the diagnosis of posttraumatic feeding disorder of infancy.  
*Journal of the American Academy for Child and Adolescent Psychiatry*,  
5: 595-602.
- Chatoor, I., Hirsch, R., Ganiban, J., Persinger, M., Hamburger, E. (1998).  
Diagnosing infantile anorexia: The observation of mother-infant  
interactions. *Journal of American Academy of Child and Adolescent  
Psychiatry*, 37, 9, 959-967
- Cicchetti, D., Rogosch, F.A. & Toth, S.L. (1998). Maternal depressive disorder  
and contextual risk: Contributions to the development of attachment  
insecurity and behaviour problems in toddlerhood. *Development and  
Psychopathology*, 10, 283-300.
- Clark, D.A., Steer, R.A., & Beck, A.T. (1994). "Common and specific  
dimensions of self-reported anxiety and depression: Implications for the  
cognitive and tripartite models". *Journal of Abnormal Psychology*, 103:  
645–654.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd  
ed.). Hillsdale, NJ: Erlbaum.
- Coulthard, H., Blissett, J. & Harris, G. (2004). The relationship between  
parental eating problems and children's feeding behavior: A selective  
review of the literature. *Eating Behaviours*, 5(2): 103-115.
- Coulthard, H. & Harris, G. (2003). Early food refusal: The role of maternal  
mood. *Journal of Reproductive and Infant Psychology*, 21, 335-345.
- Crist, W., McDonnell, P. & Beck, M. (1994). Behaviour at mealtimes and the  
young child with Cystic Fibrosis, *Journal of Behavioural*

*Pediatrics*, 15: 157-161.

Cummings, E.M. & Davies, P.T. (1994). Maternal depression and child development. *Journal of Child Psychology and Psychiatry*, 35, 73-112.

Davies, W.H., Satter, E., Berlin, K.S, Sato, A.F., Silverman, A.H., Fischer, E.A., Arvedson, J.C., & Rudolph, C.D. (2006). Re-conceptualizing feeding and eating disorders in interpersonal context: the case for a relational disorder. *Journal of Family Psychology*, 20, 409-417.

Deater-Deckard, K. (1998). *Parenting stress*. New Haven, CT: Yale University Press.

deAyala RJ, Vonderharr-Carlson DJ, Kim D (2005). "Assessing the reliability of The Beck Anxiety Inventory Scores". *Educational and Psychological Measurement*, 65 (5): 742–756.

deJong-Gierveld, J. (1985). The development of a Rasch-type loneliness scale. *Applied Psychological Measurement*, 9(3): 289-299.

Didehbani, N., Kelly, K., Austin, L., Weichmann, A. (2011). Role of Parental Stress on Pediatric Feeding Disorders. *Children's Health Care* 40 (2): 85-100.

DiTommaso, E., Spinner, B. (1993). The development and initial validation of the Social and Emotional Loneliness Scale for Adults (SELSA). *Personality and Individual Differences*, 14(1): 127-134.

Douglas, J. & Harris, B. (2001). Description and evaluation of a day-centre based behavioural feeding programme for young children and their parents. *Clinical Child Psychology and Psychiatry*, 6, 241-256.

Douglas, J.E. & Byron, M. (1996). Interview data on severe behavioural eating difficulties in young children. *Archives of Disease in Childhood*, 75, 304–30.

DSM-V. *Diagnostic and Statistical Manual of Mental Disorders American*

*Psychiatric Association*. (2013) (5th ed.). Arlington: American Psychiatric Publishing.

Dunst, C. J., Trivette, C. M., Hamby, D., & Pollock, B. (1990). Family systems correlates of behavior of young children with handicaps. *Journal of Early Intervention*, (14), 204-218.

Durak, M, Senol-Durak, E. & Gencoz, T. (2010). Psychometric Properties of the Satisfaction with Life Scale among Turkish University Students, Correctional Officers, and Elderly Adults. *Social Indicators Research*, 99(3): 413-429.

Endler, N. S., & Parker, J. D. A. (1990). "Multidimensional Assessment of Coping: A Critical Evaluation." *Journal of Personality and Social Psychology*, 58(5), 844-854.

Evans-Morris, S. & Dunn-Klein, M. (2000). Pre-Feeding Skills. Second Edition, Mealtime Notions LLC.

Farrow, C., & Blissett, J. (2006). Maternal cognitions, psychopathologic symptoms, and infant temperament as predictors of early infant feeding problems: A longitudinal study. *International Journal of Eating Disorders*, (39), 128–134.

Feldman, R., Eidelman, A.I., & Rotenberg, N. (2004). Parenting stress, infant emotion regulation, maternal sensitivity, and the cognitive development of triplets: A model for parent and child influences in a unique ecology. *Child Development*, 75: 1774– 1791.

Feldman, R., Greenbaum, C.W., Mayes, L.C., & Erlich, H.S. (1997). Change in mother–infant interactive behavior: Relations to change in the mother, the infant, and the social context. *Infant Behavior and Development*, 20, 153–165.

- Fernandez-Cossgrove, K. (2011). Autonomy, father's role, and eating disorders: A daughter's perspective. ProQuest, UMI Dissertation Publishing.
- Field., D., Garland, M. & Williams, K. (2003). Correlates of specific childhood feeding problems. *Journal of Paediatrics and Child Health*, 39(4): 299-304.
- Fischer, E. & Silverman, A. (2007). Behavioral Conceptualization, Assessment, and Treatment of Pediatric Feeding Disorders. *Seminars in Speech and Language*, 28(3): 223-231.
- Fisher, J.O., Birch, L.L., Smiciklas-Wright, H. & Picciano, M.F. (2000). Breast feeding through the first year predicts maternal control in feeding and subsequent toddler energy intakes.
- Fraley, A. M. (1990). Chronic sorrow: A parental response. *Journal of Pediatric Nursing*, 5: 268-273.
- Frankl, D. A. & Zeisl, S.H. (1988). Failure to Thrive. *Pediatric Clinics of North America*, 35: 1187-1206.
- Fees, B. S., Martin, P. & Poon, L. W. (1999). A model of loneliness in older adults. *Journal of Gerontology*, 54B: 231–239.
- Fitzgerald, F. & Lane, R.C. (2000). The role of the father in anorexia. *Journal of Contemporary Psychotherapy*, 30(1): 71–84.
- Folkman, S. & Lazarus, R. (1988). Ways of coping revised questionnaire. Palo Alto, CA: Consulting Psychologists Press.

- Franklin, L. & Rodger, S. (2003). Parents' perspectives on feeding medically compromised children: Implications for occupational therapy. *Australian Occupational Therapy Journal*, 50: 137– 147.
- Fraser, M. W., Day, S. H., Galinsky, M. J., Hodges, V. G., & Smokowski, P. R. (2004). Conduct problems and peer rejection in childhood: A randomized trial of the *Making Choices* and *Strong Families* programs. *Research on Social Work Practice*, 14(5): 313-324.
- Fydrich, T., Dowdall, D. & Chambless, D.L. (1992). Reliability and validity of the Beck Anxiety Inventory. *Journal of Anxiety Disorders* (6), 55–61.
- Gath, A. (1973). The school-age siblings of mongol children. *British Journal of Psychiatry*, 123: 161-167.
- Golik, T., Avni, H., Nehama, H., Greenfeld, M., Sivan, Y. & Tauman, R. (2013). Maternal cognitions and depression in childhood behavioral insomnia and feeding disturbances. *Sleep Medicine*, 14(3): 261-265.
- Gottmaker, S.L., Walker, D. K., Weitzman, M., & Sobol, A.M. (1990). Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. *Pediatrics*, (3), 267–276.
- Graves, J. K., & Ware, M. E. (1990). Parents' and health professionals' perceptions concerning parental stress during a child's hospitalization. *Children's Health Care*, 19: 37-42.
- Green, S. B. (1991). How many subjects does it take to do a regression analysis? *Multivariate Behavioral Research*, 26, 499-510.
- Greenspan, S.I. & Porges, S.W. (1984). Psychopathology in infancy and early childhood: Clinical perspectives on the organization of sensory and affective-thematic experience. *Child Development*, 55(1): 49-70.

- Gueron-Sela, N., Atztaba-Poria, N., Meiri, G. (2011). Maternal worries about child underweight mediate and moderate the relationship between child feeding disorders and mother-child feeding interactions. *Journal of Paediatric Psychology*, 36(7): 827-836.
- Hagekull, B., & Dahl, M. (1987). Infants with and without feeding difficulties: Maternal experiences. *International Journal of Eating Disorders*, 6 (1), 83-98.
- Harvey, L., Bryant-Waugh, R., Watkins, B., & Meyer, C. (2013). Parental perceptions of childhood feeding problems. *Journal of Child Health Care*, 19(3): 392-401.
- Harris, R. J. (1985). *A primer of multivariate statistics* (2nd ed.). New York: Academic Press.
- Harris, T. (2001). Recent developments in understanding the the psychological aspects of depression. *British Medical Bulletin*, 57(1), 17-32.
- Haskett, M. E., Ahern, L. S., Sabourin Ward, C., & Allaire, J. C. (2006). Factor structure and validity of the Parenting Stress Index/Short Form. *Journal of Clinical Child and Adolescent Psychology*, 35: 302–312.
- Hatfield, A. B., Spaniol, L. & Zippel, A. M. (1987). Expressed emotion: A family perspective. *Schizophrenia Bulletin*, 13, 221-226.
- Haywood, P. & Mccann, J. (2009). A brief group intervention for young children with feeding problems, *Clinical Child Psychology and Psychiatry*, 14, 361.
- Hellin, K. & Waller, G. (1992) Mother's mood and infant feeding: Prediction of problems and practices. *Journal of Reproductive and Infant Psychology*, 10: 39-51.

- Hyman, P.E. (1994). Gastroesophageal reflux: one reason why baby won't eat. *Journal of Pediatrics*, 125(6): 103-109.
- Jacobvitz, D., & Sroufe, L. A. (1987). The early caregiver-child relationship and attention-deficit disorder with hyperactivity in kindergarten: A prospective study. *Child Development*, 58, 1496 – 1504.
- Johannsen, D.L., Johannsen, N.M. & Specker, B.L. (2006). Influence of parents' eating behaviors and child feeding practices on children's weight status. *Obesity*. 14 (3):431-9.
- Johnson, K. P., Giannotti, F. & Cortesi, F. (2009). Sleep patterns in autism spectrum disorders. *Child and Adolescent Clinics of North America*, 18: 917–28.
- Johnson, C.R., Handen, B.L., Mayer-Costa, M. & Sacco, K. (2008). Eating habits and dietary status in young children with Autism. *Journal of Developmental and Physical Disabilities*, 20: 437–448.
- Jones, C. & Bryant-Waugh, R. (2012). Development and pilot of a group skills and support intervention for mothers of children with feeding problems. *Appetite*, 58: 450-456.
- Jones, C. (2009). Mothers of children with feeding problems: Maternal mental health and the development of a skills-and-support intervention. Doctoral Thesis. Oxford University.
- Julian, L. (2011). Measures of Anxiety: State-Trait Anxiety Inventory (STAI), Beck Anxiety Inventory (BAI), and Hospital Anxiety and Depression Scale-Anxiety (HADS-A). *Arthritis Care and Research*, 63(11): 467-472.
- Kane, P. & Garber, J. (2004). The relations among depression in fathers, children's psychopathology, and father-child conflict: A meta-analysis. *Clinical Psychology Review*, 24: 339–360.



- Kessler, R.C., Gruber, M., Hettema, J.M., Hwang, I., Sampson, N., & Yonkers, A. (2008). Co-morbid major depression and generalized anxiety disorders in the National Comorbidity Survey follow-up. *Psychological Medicine*, 38(03), 365-374.
- Krohne, H W, (1993). Vigilance and cognitive avoidance as concepts in coping research. In H W Krohne (Ed), (1993). *Attention and Avoidance. Strategies in Coping with Aversiveness* (pp. 19–50). Seattle, WA: Hogrefe & Huber.
- Lamb, M.E. (2004). *The Role of the Father in Child Development*. John Wiley & Sons.
- Lazarus, R. S. (1991). *Emotion and adaptation*. London: Oxford University Press.
- Ledford, J.R. & Gast, D.L. (2006). Feeding problems in children with autism spectrum disorders: A review. *Focus on Autism and Other Developmental Disabilities*, 21(3): 153-166.
- Levy-Shiff, R. & Israelashvili, R. (1988). Antecedents of fathering: Some further explorations. *Developmental Psychology*, 24, 434-440.
- Lewinsohn, P.M., Denoma, J.M., Gau, J.M, Joiner, T.E, Striegel- Moore, R., Bear, P., & Lamoureux, B. (2005). Problematic eating and feeding behaviors of 36-month-old children. *International Journal of Eating Disorders*, 25: 253–262.
- Lindberg, L., Bohlin, G., Hagekull, B. & Palmerus, K. (1996) Interactions between mothers and infants showing food refusal. *Infant Mental Health Journal*, 17: 334-347.

- Lindberg, L., Bohlin, G. & Hagekull, B. (1991). Early feeding problems in a normal population. *International Journal of Eating Disorders*, 10, 395-405.
- Linscheid, T. R., & Murphy, L. B. (1999). Feeding disorders of infancy and childhood. In S. D. Netherton, D. Holmes, & C. E. Walker (Eds.), *Child and adolescent psychological disorders: A comprehensive textbook* (pp. 139–155). Oxford, England: Oxford University Press.
- Linscheid, T. R., & Murphy, L. B. (1999). Feeding disorders of infancy and childhood. In S. D. Netherton, D. Holmes, & C. E. Walker (Eds.), *Child and adolescent psychological disorders: A comprehensive textbook* (pp. 139–155). Oxford, England: Oxford University Press.
- Maine, M. (2004). *Father Hunger: Fathers, Daughters and Food* Second Edition, 2004. Gurze Books, CA.
- Manikam, R. & Perman, J.A. (2000). Paediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30, 34-46.
- McCarthy, C. J. (1998). Relationship of parental attachment and gender to beliefs about mood. *Journal of College Student Psychotherapy*, 12: 39–59.
- Micali, N., Simonoff, E., & Treasure, J. (2009). Infant feeding and weight in the first year of life in babies of women with eating disorders. *Journal of Pediatrics*, 154 (1): 55-60.
- Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. *Child Development*, 56, 289-302.
- Minuchin, S., Rossman, B., & Baker, L. (1978). *Psychosomatic Families: Anorexia Nervosa in Context*. Harvard University Press: Cambridge.

- Morgan, S. B. (1988). The autistic child and family functioning: a developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18(2), 263-280.
- Mrdjenovic, G. & Levitsky, D.A. (2005). Children eat what they are served: the imprecise regulation of energy intake. *Appetite*. 44(3): 273-82.
- National Association of Anorexia Nervosa and Associated Disorders (ANAD) (2015), Eating Disorder Statistics.
- National Statistics. (2003). Better Or Worse: A Longitudinal Study Of The Mental Health Of Adults In Great Britain.
- Newton, M., Boblin, S., Brown, B. & Ciliska, D. (2006). Understanding intimacy for women with anorexia nervosa: a phenomenological approach. *European Eating Disorders Review*, 14: 45-53.
- Orrell-Valente, J. K., Hill, L. G., Brechwald, W. A., Dodge, K. A., Pettit, G. S., & Bates, J. E. (2007) Just three more bites”: An observational analysis of parents’ socialization of children's eating at mealtime. *Appetite*, 34(1): 37-45
- Oshagan, H., & Allen, R. L. (1992). Three loneliness scales: An assessment of their measurement properties. *Journal of Personality Assessment*, 59: 380– 409.
- Palmer, S. & Horn, S. (1978). Feeding problems in children. In: Palmer, S. & Ekvall, S., editors. *Pediatric nutrition in developmental disorders*. Springfield, IL: Thomas, pp. 107-129.
- Parke, R. D., & Buriel, R. (1998). Socialization in the family: Ethnic and ecological perspectives. In Damon, W. (Series ed.) and Eisenberg, N. (Vol. ed.), *Handbook of Child Psychology: Vol. 3. Social, Emotional, and Personality Development*, Wiley, New York.

- Parry, A. & Doan, R., (1994). Story re-visions: Narrative therapy in the postmodern world. New York: Guilford Press.
- Patterson, T.L., Semple, S.J., Temoshok, L.R., Atkinson, J.H., McCutchan, J.A., Straits-Troster, K.A., Chandler, J.L. & Grant, I. (1993). Depressive symptoms among HIV positive men: life stress, coping and social support. *Journal of Applied Bio-behavioural Research*, 1(1):64-87.
- Pederson, A.D., Parsons, H.G. & Dewey, D. (2004). Stress levels experienced by the parents of enterally fed children. *Child: Care, Health and Development*, 30(5): 507-513.
- Peplau, L.A., & Perlman, D. (1982). Perspectives on loneliness. In: Peplau, L.A., and Perlman, D., eds. *Loneliness: A Sourcebook of Current theory, research and therapy*. New York: Wiley-Interscience.
- Peterson, M.D., Kedia, S., Davis, S., Newman & S.D., Temple, C. (2007). Eating and Feeding are not the same: caregivers' perspectives of gastrostomy feeding for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 48(9): 713-717.
- Piazza, C. C. (2008), Feeding disorders and behavior: What have we learned?. *Developmental disabilities research reviews*, 14: 174–181.
- Piepenstock, E. (2010). Father Involvement in Feeding Problems. Doctoral Thesis. Royal Holloway University of London.
- Pridham, K. F., Hansen, M. F., Bradley, M. E., & Heighway, S. M. (1982). Issues of concern to mothers of new babies. *The Journal of Family Practice*, 14, 1079 – 1085.

- Quine, L., & Pahl, J. (1985). Examining the causes of stress in families with severely mentally handicapped children. *British Journal of Social Work*, 15: 501-517.
- Quittner, A.L., Blackwell, L.S., Cruz, I. & Schechter, M.S. (2010). The international depression & anxiety epidemiological study (TIDES): preliminary results from the United States. *Pediatric Pulmonology Journal*, 33: 445.
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., Wong, M., Walter, S. & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4:1
- Ramsay, M. (2013). Feeding skill, Appetite and Feeding Behaviours of Infants and Young Children and Their Impact on Growth and Psychosocial Development. *Encyclopedia on Early Childhood Development (online publication)*.
- Reitman, D., Currier, R., Hupp, S. D. A., Rhode, P., Murphy, M., & O Callaghan, P. (2001). Psychometric characteristics of the Parenting Scale in a Head Start Population. *Journal of Clinical Child Psychology*, 30: 514-524.
- Rempel, G.R., Colwell, S.O. & Nelson, R.P. (1988). Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics*, 82: 857–62.
- Riordan, M.M., Iwata, B.A., Finney, J.W., Wohl, M.K., & Stanley, A.E. (1984). Behavioral assessment and treatment of chronic food refusal in handicapped children. *Journal of Applied Behavior Analysis*, 17(3); 327-341.
- Rodrigue, J. R., Geffken, G. R., & Streisand, R. (1999). *Child health*

*assessment: A handbook of measurement techniques*. Needham, MA: Allyn & Bacon.

- Rogers, L., Magill-Evans, J., & Rempel, G. (2012). Mothers' challenges in feeding their children with autism spectrum disorder- Managing more than just picky eating. *Journal of Developmental and Physical Disabilities*, 24(1): 19-33.
- Rommel, N., DeMeyer, A.M., Feenstra, L., Veereman-Wauters, G. (2003). The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. *Journal of Pediatric Gastroenterology and Nutrition*. 37(1): 75-84.
- Russell, D. (1996). The UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. *Journal of Personality Assessment*, 66, 20-40.
- Russell, D., Peplau, L. A., & Cutrona, C. E. (1980). The Revised UCLA Loneliness Scale. Concurrent and discriminant validity evidence. *Journal of Personality and Social Psychology*, 39, 472–480.
- Sanders, M., Patel, R., LeGrice, B. & Shephard, R. (1993), Children with persistent feeding difficulties: an observational analysis of the feeding interactions of problem and non-problem eaters. *Health Psychology*, 12: 64–73.
- Satter, E. (1990). The feeding relationship: Problems and interventions. *Journal of Pediatrics*, 117: 181–189.
- Satter, E. (2005). *Your Child's Weight: Helping Without Harming*. Kelcy Press.
- Schore, A.N. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Mahwah, NJ: Erlbaum.

- Schore, A.N. (2005). Back to basics. Attachment, affect regulation, and the developing right brain. Linking developmental neuroscience to paediatrics. *Paediatric Review*, 26: 204–17.
- Schwarz, S.M. (2003). Feeding Disorders in Children with Developmental Difficulties. *Journal of Infants and Young Children*, 16(4): 317-330.
- Scott, J. A., Binns, A.C. & Aroni, R. (1997). "The influence of reported paternal attitudes on the decision to breast- feed." *Journal of Pediatrics and Child Health*, 33 (4): 305-307.
- Seher, C.L. (2011). Parent-Child Interaction During Feeding — How It May Influence Kids' Weight and Relationship With Food. *Today's Dietician*, 13(4): 32.
- Skuse, D. H. (1985). Non-organic failure to thrive: A reappraisal. *Archives of Disease in Childhood*, 60, 173 – 178.
- Smith, B.A. & Kaye, D.L. (2012). Treating Parents of Children With Chronic Health Conditions: The Role of the General Psychiatrist. *Clinical Synthesis*, 10: 255-265.
- Spielberger, C.D., Gorsuch, R.L., Lushene, P.R., Vagg, P.R., & Jacobs, G.A (1983). Manual for the State-Trait Anxiety Inventory. Consulting Psychologists Press, Inc.
- Stein, A., Woolley, H., Cooper, S. D., & Fariburn CL (1994) An observational study of mothers with eating disorders and their infants. *Journal of Child Psychology and Psychiatry*, 35: 733 -748.
- Sullivan, P.B., Juszczak, E., Lambert, B.R., Rose, M. Ford-Adams, M.E., Johnson, A. (2002). Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. *Journal of Developmental Medicine and Child Neurology*, 44(7): 461-7.

- Teo, A.R., Choi, H. & Valenstein, M. (2013). Social Relationships and Depression: Ten-Year Follow-Up from a Nationally Representative Study. *PLoS ONE*, 8(4).
- Thoyre, S.M., Shaker, C.S. & Pridham, K.F. (2005). The early feeding skills assessment for preterm infants. *Neonatal Network*, 24(3): 7-16.
- Twachtman-Reilly, J., Amaral, S., & Zebrowski, P. (2008). Addressing Feeding Disorders in Children on the Autism Spectrum in School-Based Settings: Physiological and Behavioral Issues. *Language, Speech, And Hearing Services in Schools*, 39: 261-272.
- Veisson M. (1999) Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behavior and Personality*. 27, 87 – 98.
- Weissman, S., & Cohen, R. S. (1985). The parenting alliance and adolescence. *Adolescent Psychiatry*, 12, 24-45.
- Whelan, E. & Cooper, P. J. (2000). The association between childhood feeding problems and maternal eating disorder: a community study. *Psychological Medicine*, 30, 69-77.
- Wickler, W. (1986). On intra-uterine mother-offspring conflict and a possible case in the pig. *Ethology*, 72: 250–253.
- Williams, J.B. (1988). A structured interview guide for the Hamilton Depression Rating Scale. *Archives of General Psychiatry*, 45(8): 742–747.
- Williams, K.E., Hendy, H. & Knecht, S. (2008). Parent feeding practices and child variables associated with childhood feeding problems. *Journal of Developmental and Physical Disabilities*, 20 (3): 231-242.



- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews*, 8, 151–161.
- Wright, C. & Birks, E. (2000). Risk factors for failure to thrive: a population based study. *Child: Care, health and Development*, 26(1): 5-16.
- Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandandania*, 67: 361–70.

## **APPENDICES**

### **Appendix 1 – Study Protocol**

Date: 09/08/2011

#### **Study Protocol**

#### **Developing Content for Skills and Support Interventions for Mothers and Fathers of Children with Feeding Disorders.**

Ms Avital Pearlman, Trainee Clinical Psychologist, University of East London Doctoral Course in Clinical Psychology.

Dr Rachel Bryant-Waugh, Consultant Clinical Psychologist and Joint Head of Feeding and Eating Disorders Service, Great Ormond Street Hospital NHS Trust.

Dr Emma Piepenstock, Clinical Psychologist, Feeding and Eating Disorder Service, Great Ormond Street Hospital NHS Trust.

#### **Research Aims:**

The general aim of the study is to add to the current evidence base on the types of issues that might usefully be addressed in interventions for mothers and fathers/primary carers of children with feeding problems and identify whether parents of children with different presentations might have different needs and priorities, suggesting the usefulness of tailored interventions. The specific aims are:

1. To gather information regarding a number of parent variables previously demonstrated as being associated with having a child with a feeding disorder to inform the development of novel interventions aimed at both parents; that is, to clarify and prioritise potentially useful areas to address in novel group/couple interventions for mothers and fathers of children with feeding problems, in particular to ensure that fathers' needs are attended to as well as mothers'.
2. To investigate differences between male and female parents on a number of key variables demonstrated to be associated with having a child with a feeding disorder or of relevance to feeding, in particular; anxiety, depression, stress, social isolation and coping style, in order to inform content and focus of novel parent interventions, to promote the potential for mutual parental understanding and support.

3. To explore whether the focus of parent interventions may need to differ according to characteristics of the child's presentation, for example; age, broad type of feeding problem (medical/non-medical; ASD/no ASD/ASD features; tube fed/ no tube), and severity of feeding disorder. We hypothesize that such characteristics might interact with parent variables in specific ways.

### **Literature Review/Rationale:**

#### **Feeding Disorders**

The incidence of feeding difficulties in children with no developmental difficulties is approximately 30 per cent (Blissett & Harris, 2002) and up to 80 per cent in children with developmental disabilities (Manikam & Perman, 2000). The DSM-IV-TR definition of 'Feeding Disorder of Early Childhood' is a feeding or eating disturbance, where the child fails to eat enough to either gain weight or causes significant weight loss over at least one month, not due to a medical condition (APA, 1994). A recent review by Bryant-Waugh et al (2010) highlights the difficulty in distinguishing whether a feeding problem is of organic or non-organic origin as they involve medical, emotional, behavioural and relational disturbances (Rommel et al., 2003).

#### **Feeding Problems within Relationships**

Bryant-Waugh & Piepenstock (2008) highlight the nature of the word 'feeding' indicates a two-way process between the care giver and child. It has been suggested that the family environment has a significant impact on the child's feeding behaviour (Mrgjenovic & Levitsky, 2005). Attachment Theory (Bowlby, 1969) views feeding as a dynamic process between care-giver and child which begins with the child indicating they are hungry and the care-giver responding appropriately. Maternal attunement facilitates the child's understanding of its internal state and ability to regulate its needs (Schore, 2005). If the mother is not attuned to her child whom she feeds to her own rigid schedule, the child is more likely to misread its own bodily signals, leaving it less able to self-regulate (Fisher et al., 2000) and ignoring its own needs in favour of the mother's.

Recent literature argues for Feeding Disorders to be re-conceptualized as a relational disorder (Davies et al, 2006), moving away from seeing the disorder as individual to the child to being a difficulty that exists between the child and the wider system (Manikam & Perman, 2000). Particular parental traits and styles seem to be more apparent in children with FDs (Bryant-Waugh et al, 2010) for example mothers more likely to be unpredictable, intrusive

and controlling, using more coercive feeding styles and are less likely to respond affectionately or be flexible in their approach toward the child (Stein et al., 1994; Chatoor et al., 1998).

There is a high incidence of mental health difficulties amongst mothers of children with feeding disorders, mostly anxiety and depression (Coulthard & Harris, 2003; Lindberg et al., 1996) and it is unclear whether they are causal or subsequent to the problem. Depressed mothers may be less sensitive and responsive to the needs of the child and may be somewhat unpredictable and unavailable (Cummings & Davies, 1994). These characteristics are associated with the onset of childhood feeding problems (Lindberg et al., 1996).

#### Feeding Problems and Developmental Delay

High levels of depression are found in parents of children with Learning Disabilities (Veisson, 1999). Parental depression has been identified as an indicator for poor outcomes in interventions for children with Learning Difficulties and behavioural problems including feeding (Brinker et al., 1994). Due to the significantly higher levels of feeding and other behavioural problems in children with global developmental delay (up to 80%) it is important to consider supporting parental coping skills. Mealtimes can be very stressful for parents (Sullivan et al., 2002) who find it difficult to entrust the feeding of their child to another. This restricts parental social activities, leaving them feeling isolated and unable to access support systems. This leaves parents exposed to increased anxiety and feelings of failure (Andrew & Sullivan, 2010).

#### Approaching Feeding Problems from a Systemic Perspective

It is helpful to understand the feeding problem from a systemic viewpoint as this removes the implication of an individual being at fault to each member of the system offering a potential solution (Parry & Doan, 1994) and enables the father to be included in the treatment. Fathers play an important role in the family, (Belsky et al., 1989; Levy-Shiff & Israelashvili, 1988) and can significantly increase maternal sensitivity, positively influencing the mother's responses to her child (Feldman et al., 1997). Co-parenting is considered important in children's development (Minuchin, 1985); a functional parenting alliance supports communication and is an immediate support system that reduces parental stress (Weissman & Cohen, 1985). There is relatively little research regarding the role of fathers in the development and treatment of feeding problems, but it is suggested that it is beneficial to include both the mother father in the treatment process (Piepenstock, 2010).

#### Parent Groups for Children with Feeding Problems

Current interventions for treating feeding problems in early childhood are largely individual, occurring within clinical settings focusing on parent-child interactions (Haywood & McCann, 2009). Although the studies focussing on group work for parents (usually mothers) are limited,

there appears to be significant improvements in those that have been trialled (Douglas & Harris, 2001; Fraser et al., 2004; Haywood & McCann, 2009). A recent study by Bryant-Waugh et al (2007), describes the development of a parenting skills and support group for mothers with eating disorders (who often have problems feeding their children). The study piloted an eight-session group to promote positive parenting practices and was found to increase confidence in parenting ability and reduce levels of depression (Bryant-Waugh et al., 2007). This study was found to be both feasible and valued by parents. Jones (2009) piloted a group for mothers of children with feeding difficulties, the group aimed to address psychopathology, parental stress, and the impact on the feeding relationship. There was no significant change in psychopathology or stress but mothers reported finding the group highly beneficial, as they felt supported and understood (Jones, 2009). Whilst the parent groups have reportedly been effective, they do not place an emphasis on father involvement. It has not been questioned whether groups should cover feeding problems as a general condition or whether groups should be developed according to, for example, severity of problem or presence or absence of significant developmental delay, which may affect the level or type of support needed.

### Rationale

Recent literature indicates that feeding problems are best managed within a systemic context (Douglas & Harris, 2001; Fraser et al., 2004; Haywood & McCann, 2009). Currently, the main body of research in this area focuses on the mother-child relationship and the complexity of the interactions that occur around the feeding difficulty (Chatoor, 1998). This relationship is pivotal in the feeding relationship and must be addressed in the treatment of feeding problems. However it must be acknowledged that the mother-child relationship does not exist in isolation. The role of the father has received little attention in the treatment of feeding problems both in the literature and clinically. It has been established that fathers play an important role in the healthy development of the child and in the enhancement of the mother-child relationship (Feldman et al., 1997), both of which need to be attended to when treating children with feeding problems.

No evidence-based group interventions could be found that involve both parents in the treatment of feeding disorders. A recent study by Piepenstock (2010) indicates that fathers of children with feeding problems display higher levels of stress than those where feeding problems are not present. This is likely to impact on all the relationships within the family system, perhaps leading the father to reduce his involvement with members of the family or feeling less able to support the treatment of the child. There is research to suggest that paternal eating behaviour also plays a role in the development of childhood feeding and eating practices (Johannsen et al., 2006) and that lower paternal involvement is more common in families where a child has a feeding disorder compared to control groups (Atzaba-Poria et al., 2010). It

is therefore indicative that fathers should be included in the treatment of feeding problems, as they have a potentially valuable role to play.

Whilst there are relatively few skills and support interventions for parents of children with feeding problems that have been documented, those that have been evaluated have been well received. However as there has not been a group where both parents are invited to participate, there is little indication as to what topics would be useful to both mothers and fathers. This research would be an initial stage in the development of novel interventions for parents, and be used as an identifier of the differences in experience between parents on a number of key variables that are relevant in feeding (e.g. anxiety, depression, stress, social isolation, coping). This would be useful in deciding the content of the support group, as more prevalent issues would be given greater weighting. The investigation may also identify whether other variables - such as age of the child, presence of global developmental delay or whether the feeding problem is medical in origin - affect parents differently and thus shed light on whether separate support groups need to be run accordingly.

Once this study has been conducted the longer-term aim is to target fathers to take part in treatment alongside mothers and for the content of interventions to be considered according to the finding of this study. The longer-term aim is to disseminate findings to other services and for the content of interventions to be informed by this study.

### **Design:**

Based on a review of the existing literature, five factors have been identified that are either associated with being a parent of a child with a feeding disorder or have been shown to be relevant to feeding. Importantly, all are also demonstrated as being amenable to change through targeted intervention. These include; stress, depression, anxiety, social isolation and avoidant coping style. Following the identification of these factors, a set of questionnaires has been identified that map on to these factors: Parent-Stress Index-36 (Abidin,1995), Beck Depression Inventory (Beck, 1996), Beck Anxiety Inventory (Beck, 1990), UCLA Loneliness Scale (Russell, 1996) and the COPE Scale (Carver, Scheier, & Weintraub, 1989).

An initial focus group will be carried out with approximately 6-8 mothers and fathers of children with feeding disorders, in a semi-structured manner, in order to explore the relative relevance of the areas identified from the literature to both mothers and fathers with experience of parenting a child with a feeding disorder, and to identify themes within each construct area that parents feel might be helpful to address in the process of managing a child's feeding problem. The group discussion will be facilitated, recorded and transcribed and a Thematic Analysis will be conducted (parents will be informed of the purpose of the focus group and be asked to provide written consent for the discussion to be recorded and used in this way). The parents who take part in the focus group will be asked to join in discussion for one to one and a half hours. They will not be asked to take part in the second part of the research.

The second part of the study will use a quantitative, questionnaire based design. Parents of children attending the clinic will be contacted via a letter outlining the purpose of the study and explaining that both mothers and fathers will each receive a set of five questionnaires regarding areas that have been previously identified as being potentially relevant in parenting a child with a feeding disorder. They will also be asked for basic demographic information regarding themselves and their child. Parents will additionally be asked to complete the Behavioural Feeding Assessment Scale (BPFAS) (Crist et al, 1994) as a measure of perceived severity of their child's feeding problem. Permission will be requested for the researchers to use objective measures such as weight centile, growth, centile, BMI centile and presence of tube dependency at assessment as markers of severity. Opportunity to discuss any questions will be provided as part of the process of seeking consent. It is hoped that approximately 40 sets of mothers and fathers will be recruited to take part in the second stage of the research. However a previous study of a similar nature (Piepenstock, 2010) achieved highly powered analyses in regressions including parental factors and child feeding (e.g. effect size of 0.37 and power of 0.94) with 42 sets of parents. It is therefore thought that the number of parents being recruited will be adequate to produce a meaningful outcome.

No control group is needed as the first part of the study is exploratory, aimed at checking whether variables identified from the literature resonate with a group of parents of children with clinically significant feeding difficulties, and identifying specific themes within each area that participants feel might be useful to address in skills and support interventions aimed at both parents. For the second part, a control group is also not indicated, as the aim is to identify differences in relevant areas to address within a heterogeneous clinic population. Once the questionnaires have been returned, parents will not be asked for any further participation.

#### **Data Analysis:**

- Thematic Analysis will be used to analyse the focus group.
- To investigate the differences between mothers and fathers on the 5 identified parent variables a series of t-tests will be used.
- A series of correlations will be carried out between age and severity of disorder and parent variables, controlling for multiple correlations. Variables found to be significantly correlated will be entered in to multiple regressions to investigate the impact of these variables on age and severity.
- A series of 3 MANOVAs will be conducted to investigate the impact of type of feeding disorder on the 5 variables.

#### **Ethical Considerations**

It is not thought likely that participants will find taking part in the research to have any disadvantages. However, the questionnaires may bring up some issues that may be upsetting to some participants. The researchers can be contacted if there are any issues that arise, and participants will also be advised to speak to the clinician involved in their child's care. It will be explained to participants that if any issues relating to risk arise, these will be shared according to NHS guidelines. If the participants score above the clinical cut off on the BDI they have been informed that the clinician involved in their child's care will be made aware and a referral to the GP will be made if appropriate. This has been indicated on the consent forms and the information sheet. Due to the nature of the difficulties faced by children of the participants, the researchers are aware that participants may be stressed and short of time. The focus group will therefore be kept to one to one and a half hours and the questionnaire battery should take approximately 45minutes to complete. Participants will not be asked to take part in both elements of the study in order to reduce the level of inconvenience to families.

If a participant wishes to withdraw from the study at any time, they can do so without explanation. It will be requested that they inform the researcher that they wish to withdraw in order that they are not contacted again. The participants will be made aware that withdrawal from the research will not affect their child's treatment in any way.

All data from the participants will be anonymised and coded. Any identifying data will be kept separately. All data will be kept in locked storage facility when not in use. Only the researchers will have access to the data.



## **Appendix 2 – Participant Information Sheet**

# **Great Ormond Street Hospital for Children**



NHS Trust

Great Ormond Street  
London WC1N 3JH

Tel: 020 7405 9200

### **Participant Information Sheet**

**Version 2: 15.10.2011**

#### **DEVELOPING CONTENT FOR SKILLS AND SUPPORT INTERVENTIONS FOR MOTHERS AND FATHERS OF CHILDREN WITH FEEDING DISORDERS**

I would like to invite you to take part in a research study. Before deciding whether you would like to take part, please read the following information sheet. This will explain why the research is being carried out, how it is being conducted and what it will involve for you. Please feel able to discuss the research with others if you wish to. Do not hesitate to approach the researcher or others in the service if you are not clear or would like any further information.

Thank you for taking the time to read this.

#### **1. What is the purpose of the study?**

The aim of the study is to understand the different experiences of mothers and fathers of a child with feeding problems and how this can help develop content for skills and support interventions for both parents. It has been found that both mothers and fathers are affected by their child's feeding problem and that both parents play an important role in their child's treatment. The study hopes to inform the content of parent interventions to make them useful and accessible to both parents and in turn help the treatment of the child.

#### **2. Why have I been invited to take part?**

You are being asked to take part as you are the mother or father of a child between 9 months and 8 years of age who currently display difficulties with feeding and have been referred to the Feeding Disorders Service at Great Ormond Street Hospital.

#### **3. Do I have to take part?**

It is entirely your choice whether or not you would like to take part in the study. If you make the decision to take part, you will be asked to sign a consent form, saying that you have agreed to take part. However, you are free to withdraw from the study at any time without giving a reason.

#### **4. What will happen if I take part?**

If you do wish to take part, you will be asked to fill out five questionnaires about the different experiences mothers and fathers may have when parenting a child with feeding problems. These include questions on depression, anxiety, coping skills, social isolation and stress. For the research to be useful we would like to ask mothers and fathers to each fill out a separate set of questionnaires. This will help us to understand the differences in the difficulties faced. We will also ask you to give further information about yourselves and your child, information about your child only needs to be filled out once per family.

The researcher would like to access your child's psychology notes in order to gain more detailed information about your child's feeding disorder (no other information will be accessed). You will be asked to give written consent for this to occur. You do not have to give consent to this section in order to take part in the study.

#### **5. What are the potential advantages/disadvantages of taking part?**

We cannot be certain that the study will help you directly, but we hope that the information gathered from this study will help to improve the treatment of children with feeding problems and gain a better understanding of the challenges faced by parents.

We do not think it is likely that you will find taking part in the research to have any disadvantages. However, we are aware that the questionnaires can bring up some issues that may be upsetting to some participants, as some questions refer to self harm and suicidality. The researcher can be contacted if there are any issues that arise, we would also advise you speak to the clinician involved in your child's care. We are also aware that as parents you are likely to be very busy, but we hope that the approximate time of 45 minutes to complete the study will not inconvenience you too much.

If at the time of taking part it becomes apparent that you are suffering from significant distress, anxiety or at risk of self harm, we would ask your permission to contact your GP (or psychiatrist if applicable) in order that s/he is aware of how you are feeling and so that you can receive further support. We have asked for your consent to do so on the consent form however we would talk to you about it again prior to making contact.

#### **6. What if there is a problem**

If you have concerns regarding this study, please contact the researchers involved in the study who will do their best to answer any queries. The researchers include Dr Rachel Bryant-Waugh (Consultant Clinical Psychologist) and Avital Pearlman (Trainee Clinical Psychologist).

If you continue to be unhappy and would like to make a formal complaint, please follow the NHS Complaints procedure. This can be found at the Patient Advice Liaison Services at Great Ormond Street Hospital.

#### **7. Will my taking part in the study be kept confidential?**

All data will be stored according to ethical and legal practices. All information about you will remain confidential. Your name will not appear on any documents and will be locked in a cabinet at Great Ormond Street Hospital. The clinician you are seeing will be told you are taking part, so you will be able to discuss the research with them if you so wish. They will not have access to the data unless to wish to share it with them. Confidentiality will be maintained at all times unless we are concerned about your safety or someone else's. You would be informed if we felt the need to share any concerns.

#### **8. What will happen to the results of the research?**

It is hoped that the outcome of the research will be published in a relevant journal or presented at conference. Participants would not be identified in any way. If you take part in the study you can request to have a summary of the results posted to you on completion. You will be given the option to request this on the consent form.

#### **9. Who has reviewed the study?**

The research has been reviewed by an independent NHS Research Ethics Committee, a Great Ormond Street Ethics Committee and the University of East London. They aim to protect the interests of the participants.

Please keep this information sheet for reference or if you have any queries at any stage of the research.

Thank you for time and help.

Yours sincerely,

Avital Pearlman  
Trainee Clinical Psychologist

Researcher Details:

## **Appendix 3 – Consent Form**

**Great Ormond Street **  
**Hospital for Children**  
NHS Trust

Great Ormond Street  
London WC1N 3JH  
Tel: 020 7405 9200

**Version 2: 15.10.2011**

### **CONSENT FORM**

Research Project: **Developing Skills and Support Interventions for Mothers and Fathers of Children with Feeding Disorders**

Ms Avital Pearlman

Please sign all the points below in the boxes provided and sign, name and date the form:

I have read the information sheet about this study dated \*\*\*\*

I understand that I am free to withdraw from the study at any time,  
without giving a reason with and my child's treatment will not be affected.

I understand that relevant sections of my child's medical notes and  
data collected during the research may be looked at by researchers involved in  
the study. I give permission for these individuals to have access to my  
child's records.

I agree to give permission for the researcher to contact my GP if there is  
concern about my level of distress, anxiety or risk of self-harm.\*

I agree to participate in this study.

Signed..... Name ..... Date .....

### **Person taking consent**

Signed..... Name ..... Date .....

NB: This Consent form will be stored separately from the responses you provide.

If you would like to receive a summary of the research findings once the research is completed please  
tick this box ☐ and provide a name and address for this purpose.

Name:

Address:

\* See point 5 on the information sheet for more detail

## **Appendix 4 – Questionnaire Pack**

# Great Ormond Street Hospital for Children NHS Trust

Great Ormond Street  
London WC1N 3JH

Tel: 020 7405 9200

### **Questionnaire Pack**

#### **Developing Content for Skills and Support Interventions for Mothers and Fathers of Children With Feeding Disorders**

Thank you for agreeing to take part in this study. Please fill out the questionnaires below.

#### **Beck Depression Inventory**

**Instructions:** This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

<b>1. Sadness</b>	0. I do not feel sad	1. I feel sad much of the time	2. I am sad all the time	3. I am so sad or unhappy that I cannot stand it
<b>2. Pessimism</b>	0. I am not discouraged about my future	1. I feel more discouraged about my future than I used to be	2. I do not expect things to work out for me	3. I feel my future is hopeless and will only get worse
<b>3. Past Failure</b>	0. I do not feel like a failure	1. I have failed more than I should have	2. As I look back, I see a lot of failures	3. I feel I am a total failure as a person
<b>4. Loss of Pleasure</b>	0. I get as much pleasure as I ever did from the things I enjoy	1. I don't enjoy things as much as I used to	2. I get very little pleasure from the things I used to enjoy	3. I can't get any pleasure from the things I used to enjoy
<b>5. Guilty Feelings</b>	0. I don't feel particularly guilty	1. I feel guilty over many things I have done or should have done	2. I feel quite guilty most of the time	3. I feel guilty all of the time
<b>6. Punishment Feelings</b>	0. I don't feel I am being	1. I feel I may be punished	2. I expect to be punished	3. I feel I am being

	punished			punished
<b>7. Self-Dislike</b>	0. I feel the same about myself as ever	1. I have lost confidence in myself	2. I am disappointed in myself	3. I dislike myself
<b>8. Self-Criticism</b>	0. I don't criticise or blame myself more than usual	1. I am more critical of myself than I used to be	2. I criticise myself for all of my faults	3. I blame myself for everything bad that happens
<b>9. Suicidal Thoughts or Wishes</b>	0. I don't have any thoughts of killing myself	1. I have thoughts of killing myself, but I would not carry them out	2. I would like to kill myself	3. I would kill myself if I had the chance
<b>10. Crying</b>	0. I don't cry any more than I used to	1. I cry more than I used to	2. I cry over every little thing	3. I feel like crying, but I can't
<b>11. Agitation</b>	0. I am no more restless or wound up than usual	1. I feel more restless or wound up than usual	2. I am so restless or agitated that it's hard to stay still	3. I am so restless or agitated that I have to keep moving or doing something
<b>12. Loss of Interest</b>	0. I have not lost interest in other people or activities	1. I am less interested in other people or things than before	2. I have lost most of my interest in other people or things	3. It's hard to get interested in anything
<b>13. Indecisiveness</b>	0. I make decisions about as well as ever	1. I find it more difficult to make decisions than usual	2. I have much greater difficulty in making decisions than I used to	3. I have trouble making any decisions
<b>14. Worthlessness</b>	0. I do not feel I am worthless	1. I don't consider myself as worthwhile and useful as I used to	2. I feel more worthless as compared to other people	3. I feel utterly worthless
<b>15. Loss of energy</b>	0. I have as much energy as ever	1. I have less energy than I used to have	2. I don't have enough energy to do very much	3. I don't have enough energy to do anything
<b>16. Changes in Sleeping Pattern</b>	0. I have not experienced any change in my sleeping	1a. I sleep somewhat more than usual	2a. I sleep a lot more than usual 2b. I sleep a lot	3a. I sleep most of the day 3b. I wake up

	pattern	1b. I sleep somewhat less than usual	less than usual	1-2 hours early and can't get back to sleep.
<b>17. Irritability</b>	0. I am no more irritable than usual	1. I am more irritable than usual	2. I am much more irritable than usual	3. I am irritable all the time
<b>18. Changes in Appetite</b>	0. I have not experienced any change in appetite	1a. My appetite is somewhat less than usual 1b. My appetite is somewhat greater than usual	2a. My appetite is much less than before 2b. My appetite is much greater than usual	3a. I have no appetite at all 3b. I crave food all the time
<b>19. Concentration Difficulty</b>	0. I can concentrate as well as ever	1. I can't concentrate as well as usual	2. It's hard to keep my mind on anything for very long	3. I find I can't concentrate on anything
<b>20. Tiredness or Fatigue</b>	0. I am no more tired or fatigued than usual	1. I get tired or fatigued more easily than usual	2. I am too tired or fatigued to do a lot of the things I used to do	3. I am too tired or fatigued to do most of the things I used to do
<b>21. Loss of Interest in Sex</b>	0. I have not noticed any recent change in my interest in sex	1. I am less interested in sex than I used to be	2. I am much less interested in sex now	3. I have lost interest in sex completely

### The Brief COPE

These items deal with ways you've been coping with the stress in your life since you became aware of your child's feeding difficulties. Different people deal with things in different ways, each item says something about a particular way of coping. It would be helpful to know to what extent you've been doing what each item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Please use the response choices below and try to make your answers as true for you as you can.

1 = I haven't been doing this at all

2 = I have been doing this a little bit

3 = I have been doing this a medium amount

4 = I have been doing this a lot

	1	2	3	4
1. I've been turning to work or other activities to take my mind off things.				
2. I've been concentrating my efforts on doing something about the situation I'm in.				
3. I've been saying to myself "this isn't real.".				
4. I've been using alcohol or other drugs to make myself feel better.				
5. I've been getting emotional support from others.				
6. I've been giving up trying to deal with it.				
7. I've been taking action to try to make the situation better.				
8. I've been refusing to believe that it has happened.				
9. I've been saying things to let my unpleasant feelings escape.				
10. I've been getting help and advice from other people.				
11. I've been using alcohol or other drugs to help me get through it.				
12. I've been trying to see it in a different light, to make it seem more positive.				
13. I've been criticizing myself.				
14. I've been trying to come up with a strategy about what to do.				
15. I've been getting comfort and understanding from someone.				
16. I've been giving up the attempt to cope.				
17. I've been looking for something good in what is happening.				
18. I've been making jokes about it.				
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				

20. I've been accepting the reality of the fact that it has happened.				
21. I've been expressing my negative feelings.				
22. I've been trying to find comfort in my religion or spiritual beliefs.				
23. I've been trying to get advice or help from other people about what to do.				
24. I've been learning to live with it.				
25. I've been thinking hard about what steps to take.				
26. I've been blaming myself for things that happened.				
27. I've been praying or meditating.				
28. I've been making fun of the situation.				



### UCLA Loneliness Scale

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by using the rating scale below and tick the box that corresponds with your response.

1 = Never

2 = Rarely

3 = Sometimes

4 = Always

	1	2	3	4
1. How often do you feel that you are in tune with the people around you?				
2. How often do you feel that you lack companionship?				
3. How often do you feel that there is no one you can turn to?				
4. How often do you feel alone?				
5. How often do you feel part of a group of friends?				
6. How often do you feel that you have a lot in common with the people around you?				
7. How often do you feel that you are no longer close to anyone?				
8. How often do you feel that your interests and ideas are not shared by those around you?				
9. How often do you feel outgoing and friendly?				
10. How often do you feel close to people?				
11. How often do you feel left out?				
12. How often do you feel that your relationships with others are not meaningful?				
13. How often do you feel that no one really knows you well?				
14. How often do you feel isolated from others?				

15. How often do you feel you can find companionship when you want it?				
16. How often do you feel that there are people who really understand you?				
17. How often do you feel shy?				
18. How often do you feel that people are around you but not with you?				
19. How often do you feel that there are people you can talk to?				
20. How often do you feel that there are people you can turn to?				

### Beck Anxiety Inventory

Below is a list of common anxiety symptoms. Please indicate how much you have been bothered by these symptoms during the past two weeks, including today. Please tick the box that corresponds with how you have been feeling.

	None, it didn't bother me at all.	Mildly, it didn't bother me much.	Moderately, it was unpleasant at times.	Severely, it bothered me a lot.
Numbness or tingling				
Feeling hot				
Wobbliness in legs				
Unable to relax				
Fear of the worst happening				
Dizzy or lightheaded				
Heart pounding or racing				
Unsteady				
Terrified or afraid				
Nervous				
Feeling of choking				
Hands trembling				
Shaky or unsteady				
Fear of losing control				
Difficulty in				

breathing				
Fear of dying				
Scared				
Indigestion				
Faint or lightheaded				
Face flushed				
Hot or cold sweats				

**Thank you for taking the time to complete the questionnaires. If you wish to get in contact with the research team, the details are provided on the information sheet. We would be pleased to hear from you.**

## **Appendix 5 –Demographic Questionnaire**

Great Ormond Street   
Hospital for Children  
NHS Trust

Great Ormond Street  
London WC1N 3JH  
Tel: 020 7405 9200

### **Demographic Information**

Please fill in the information regarding your child who has been referred for treatment  
at Great Ormond Street Hospital

**Parental Age:** Mother: \_\_\_\_\_ Father: \_\_\_\_\_

**Marital Status:** (please circle any that apply)

Married / Co-habiting / Separated / Divorced / Mother living with new partner /  
Father living with new partner/ Other (please state) \_\_\_\_\_

**Parental History of Feeding/Eating Disorder:** Mother: Yes / No Father: Yes / No

**Parental History of Mental Health Problems:** Mother: Yes / No Father: Yes / No

**Religion/Ethnicity:** (please state) \_\_\_\_\_

**Sex of Child:** Male / Female

**Age of Child:** \_\_\_\_\_

**Number of Siblings living at home with child:** \_\_\_\_\_

**Parental Understanding of your Child's Feeding Disorder:** (please tick any that apply)

- Selective eater
- Tube – fed (nasogastric tube / gastrostomy tube)
- Feeding problems due to medical problems
- Feeding problems due to previous or current reflux
- Feeding problems due to previous or current gut problems
- Emotional or behavioural feeding problems
- Feeding problems due to oromotor difficulties
- Feeding problems related to developmental delay
- Feeding problems related to Autism Spectrum Disorder

**Has your child got a history of medical difficulties**  
**(e.g. gut problems/severe reflux)?** Yes / No

**Does your child have a diagnosis of Autism Spectrum Disorder?** Yes / No

**Does your child have a developmental delay?** Yes / No

If your answer is yes, please could you state if they have a mild, moderate or severe delay

**Does your child attend a specialist school or nursery?**  
**Appendix 6 – BPFAS**

Yes / No

**Behavioral Pediatrics Feeding Assessment - Behavior Section**

Child's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Person Completing this Form \_\_\_\_\_

Directions: Below are a series of phrases that describe children's eating behaviors and parent's feelings about or strategies for dealing with these behaviors. Please: 1) circle the number describing how often the behavior currently occurs and 2) circle "yes" or "no" to indicate whether the behavior is currently a problem to you.

	NEVER	SOMETIMES	ALWAYS	PROBLEM		
<b>MY CHILD:</b>					<b>FOR YOU</b>	
1. Eats fruits.	1	2	3	4	5	YES NO
2. Has problems chewing food.	1	2	3	4	5	YES NO
3. Enjoys eating.	1	2	3	4	5	YES NO
4. Chokes or gags at mealtime.	1	2	3	4	5	YES NO
5. Will try new foods.	1	2	3	4	5	YES NO
6. Eats meat and/or fish.	1	2	3	4	5	YES NO
7. Takes longer than 20 minutes to finish a meal.	1	2	3	4	5	YES NO
8. Drinks milk.	1	2	3	4	5	YES NO
9. Comes readily to mealtime.	1	2	3	4	5	YES NO
10. Eats junky snack food but will not eat at mealtime.	1	2	3	4	5	YES NO
11. Vomits just before, at, or just after mealtime.	1	2	3	4	5	YES NO
12. Eats only ground, strained or soft food.	1	2	3	4	5	YES NO
13. Gets up from table during meal.	1	2	3	4	5	YES NO
14. Lets food sit in his/her mouth and does not swallow it.	1	2	3	4	5	YES NO
15. Whines or cries at feeding time.	1	2	3	4	5	YES NO
16. Eats vegetables.	1	2	3	4	5	YES NO
17. Tantrums at mealtimes.	1	2	3	4	5	YES NO
18. Eats starches (for example, potato noodles).	1	2	3	4	5	YES NO
19. Has a poor appetite.	1	2	3	4	5	YES NO
20. Spits out food.	1	2	3	4	5	YES NO
21. Delays eating by talking.	1	2	3	4	5	YES NO
22. Would rather drink than eat.	1	2	3	4	5	YES NO
23. Refuses to eat meals but requests food immediately after the meal.	1	2	3	4	5	YES NO
24. Tries to negotiate what s/he will eat and what s/he will not eat.	1	2	3	4	5	YES NO
25. Has required supplemental tube feeds to maintain proper nutritional status.	1	2	3	4	5	YES NO
<b>PARENT:</b>						
26. I get frustrated and/or anxious when feeding my child.	1	2	3	4	5	YES NO
27. I coax my child to get him/her to take a bite.	1	2	3	4	5	YES NO
28. I use threats to get my child to eat.	1	2	3	4	5	YES NO
29. I feel confident my child gets enough to eat.	1	2	3	4	5	YES NO
30. I feel confident in my ability to manage my child's behavior at mealtime.	1	2	3	4	5	YES NO
31. If my child does not like what is being served, I make something else.	1	2	3	4	5	YES NO
32. When my child has refused to eat, I have put the food in his/her mouth by force if necessary.	1	2	3	4	5	YES NO
33. I disagree with other adults (for example, my spouse the child's grandparents) about how to feed my child.	1	2	3	4	5	YES NO
34. I feel that my child's pattern hurts his/her general health.	1	2	3	4	5	YES NO
35. I get so angry with my child at mealtimes that it takes me a while to calm down after the meal.	1	2	3	4	5	YES NO

©William B. Crist, Ph.D. IWK Health Centre, Halifax, Nova Scotia. William.crist@iwbk.nshealth.ca

## **Appendix 7 – UEL Ethical Approval**



Avital Pearlman  
Garden Flat, 118 Belsize Road  
South Hampstead  
London NW6 4BG

19 May 2011

**Student Number: u0933895**

Dear Avital,

### **Registration as a Candidate for the University's Research Degree**

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

**Title of Professional Doctorate:** Professional Doctorate in Clinical Psychology

**Director of Studies:** Dr Matthew Jones Chesters

**Supervisor/s:** Dr Neil Rees

**Expected completion:** According to your actual date of registration, which is **1 October 2009**, the registration period is as follows:

**Minimum 18 months, maximum 48 months (4 years), according to a full time mode of study.**

Your thesis is therefore due to be submitted between:

<b>1 April 2012 and 1 October 2014</b>
--

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

A handwritten signature in black ink that reads 'James J. Walsh'.

Dr James J Walsh  
School Research Degrees Leader  
Direct line: 020 8223 4471  
Email: j.j.walsh@uel.ac.uk

Cc: Dr Matthew Jones Chesters

## **Appendix 8 – GOSH Ethical Approval**



Joint Research and Development Office  
Division of Research and Innovation  
**Direct Line:** 020 7905 2698  
**Email:** Marice.Lunny@gosh.nhs.uk

16/08/2012

Ms Avital Pearlman  
Lower Flat  
118 Belsize Road  
London  
NW6 4BG

Dear Ms Pearlman

<b>PROJECT TITLE</b>	Developing content for skills and support interventions for mothers and fathers of children with feeding disorders
<b>Protocol version</b>	1
<b>Protocol date</b>	09 August 2011
<b>REC Reference</b>	11/LO/1376
<b>R&amp;D Reference</b>	11BS13
<b>CSP Reference</b>	n/a
<b>Sponsor</b>	GOSH
<b>Chief Investigator (CI)</b>	Ms Avital Pearlman

### **Notification of Great Ormond Street Hospital NHS Permission.**

The research approval process for the above named study has been completed successfully. I am pleased to issue approval on behalf of Great Ormond Street Hospital for Children NHS Trust (GOSH) for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DoH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principle Investigator (PI) must ensure compliance with protocol and advise the Joint R&D Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study

Joint Research and Development Office  
Division of Research and Innovation  
UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH  
Tel: 020 7905 2179 Fax: 020 7905 2201  
www.gosh.nhs.uk

Page 1 of 2

Non-CTIMP approval V2.0

The child first and always  
11BS13



UCL INSTITUTE OF CHILD HEALTH

Great Ormond Street   
Hospital for Children

NHS Foundation Trust

Joint Research and Development Office  
Division of Research and Innovation

protocol and Sponsor requirements. Adverse Incidents (AEs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.

- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office.
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.

Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

**Marice Lunny**  
Senior Research Governance Manager  
Joint Research and Development Office

cc: Dr Rachel Bryant Waugh, GOSH  
Dr Matthew Jones-Chesters, UEL  
Dr Neil Rees, UEL

Joint Research and Development Office  
Division of Research and Innovation  
UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH  
Tel: 020 7905 2179 Fax: 020 7905 2201  
[www.gosh.nhs.uk](http://www.gosh.nhs.uk)

Page 2 of 2

Non-CTIMP approval V2.0

The child first and always

11BS13



## Tracey Dowdall - 11BS13 - CRAC Feedback

---

**From:** Tracey Dowdall  
**To:** waughr@gosh.nhs.uk  
**Date:** 7/5/2011 14:21  
**Subject:** 11BS13 - CRAC Feedback

---

**Title:** Developing content for skills and support intervention for mothers and fathers of children with feeding disorders  
**R&D Ref:** 11BS13  
**Funding:** Clinical Own Account

Dear Dr Bryant-Waugh

Thank you for attending the recent Clinical Research Adoptions Committee and providing clarification on some of the issues raised by the Committee.

You and Avital Pearlman addressed the following:

1. The Committee asked if there is a predefined family structure that the participants would be recruited from and whether this would have any effect on the results.

It was explained that this would be addressed in the way the patients are seen clinically whether the parents are biological or not. It will be whoever they are living with and is most involved with the feeding.

2. The age range is quite specific of 9 months to 7.9 years. It was asked whether there was a particular reason for this.

It was replied that it is based on the behavioural feeding assessment scale and the majority of the children that you see are in the middle of that age range.

3. It was asked how will the child's characteristics or other factors like aetiology of feeding demographic be defined.

You explained that you would be keeping it simple and it would be done on the basis of a clinical decision, there would be a mixed group some of which may have gastro problems and others there may be no history.

4. It was questioned as to the justification of recruiting 40 pairs or parents.

You confirmed that you had just gone for what you felt was the most appropriate and that it was hard to be specific.

5. It was noted that there is no control for the qualitative part of the study and asked as to why this was.

It was explained that you felt a control was not required. In your previous study you focused more on the father's experiences and the impact on them.

The Committee discussed the responses and have approved the study. You will shortly

file:///C:/Documents and Settings/DowdaT/Local Settings/Temp/XPGpWise/4E131D... 05/07/2011

receive a checklist of documents that are required for R&D approval, once everything is in place you receive an R&D approval email and you can commence your project.

Regards

Tracey

Tracey Dowdall  
Personal Assistant  
Joint GOSH/ICH Research & Development Office  
30 Guilford Street  
London WC1N 1EH

Tel: 020 7905 2700

## **Appendix 9 – NHS Ethical Approval**



### **National Research Ethics Service**

#### **NRES Committee London - Riverside**

South West Research Ethics Committee  
Level 3 Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT

Telephone: 01173421385  
Facsimile: 01173420445

03 November 2011

Ms Avital Pearlman  
Lower Flat  
118 Belsize Road  
London  
NW6 4BG

Dear Ms Pearlman

**Study title:** Developing Content for Skills and Support Interventions  
for Mothers and Fathers of Children with Feeding  
Disorders  
**REC reference:** 11/LO/1376

Thank you for your letter of 27 October 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

The Chair was content with the changes made but advised that it would be a good idea to have something either in the title or the footer of the PIS to distinguish the two PISs to avoid potential confusion.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### **Non-NHS sites**

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to the South Central Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	1 (For Focus Group - includes instructions)	09 August 2011
Investigator CV		09 August 2011
Other: Summary CV for supervisor (student research)	1	09 August 2011
Participant Consent Form: Participant Consent Form	2	15 October 2011
Participant Consent Form: Participant Consent Form	2	15 October 2011
Participant Information Sheet: Participant Information Sheet	2	15 October 2011
Participant Information Sheet: Participant Information Sheet	2	15 October 2011
Protocol	1	09 August 2011
Questionnaire: Validated	1	09 August 2011
REC application	1	09 August 2011
Response to Request for Further Information		

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- 
- Notifying substantial amendments
  - Adding new sites and investigators
  - Notification of serious breaches of the protocol
  - Progress and safety reports
  - Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

**Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**11/LO/1376**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr Sabita Uthaya**  
**Chair**

Email: ubh-tr.RiversideREC@nhs.net

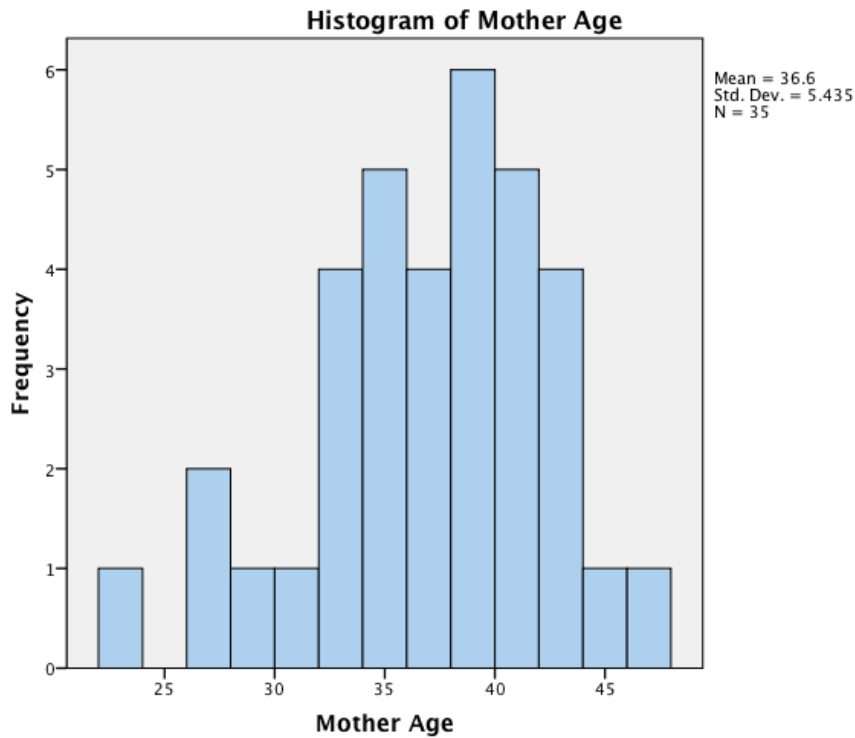
Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Ms Nima Sharma, Research & Development GOSH NHS Trust &  
Institute of Child Health  
sharmn1@gosh.nhs.uk

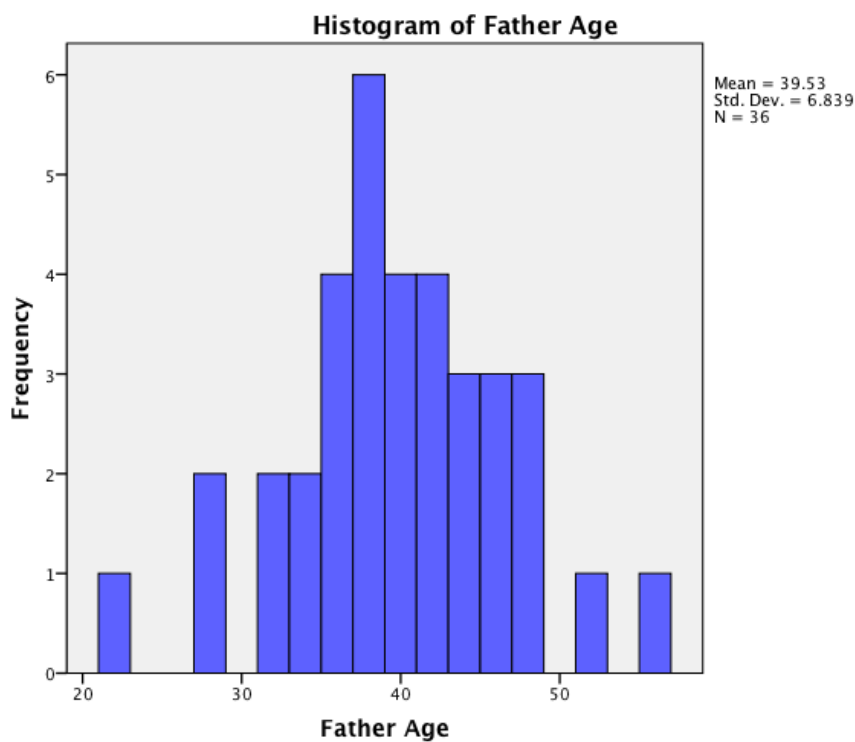


## **Appendix 10 – Exploratory Data Histograms**

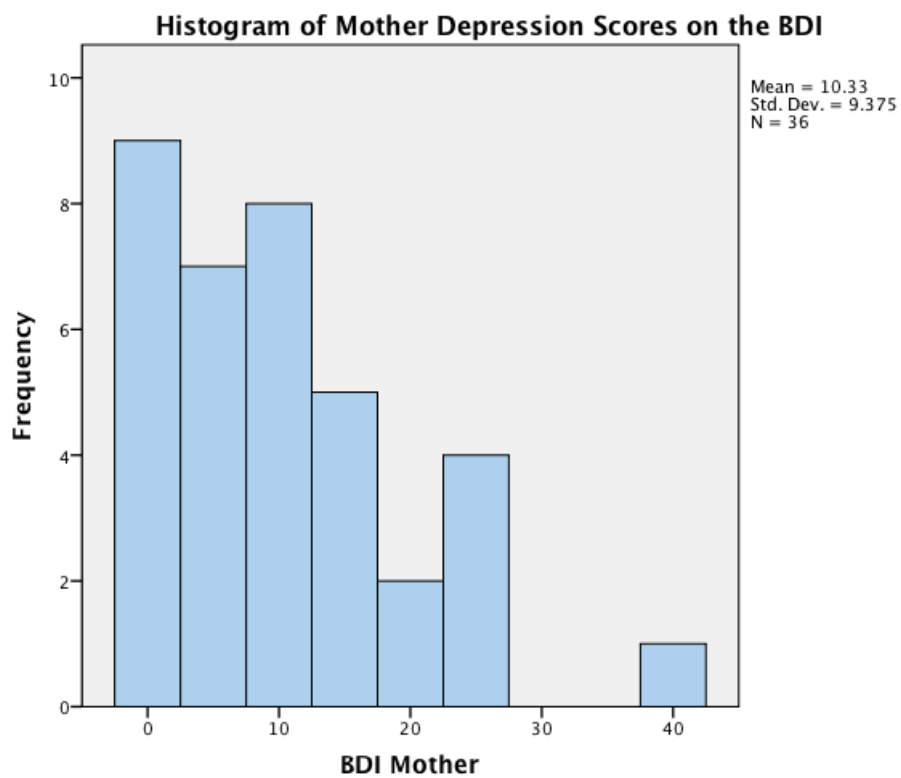
**Figure 4.1:** Histogram to Show the Spread of Mother Age within the Research Sample



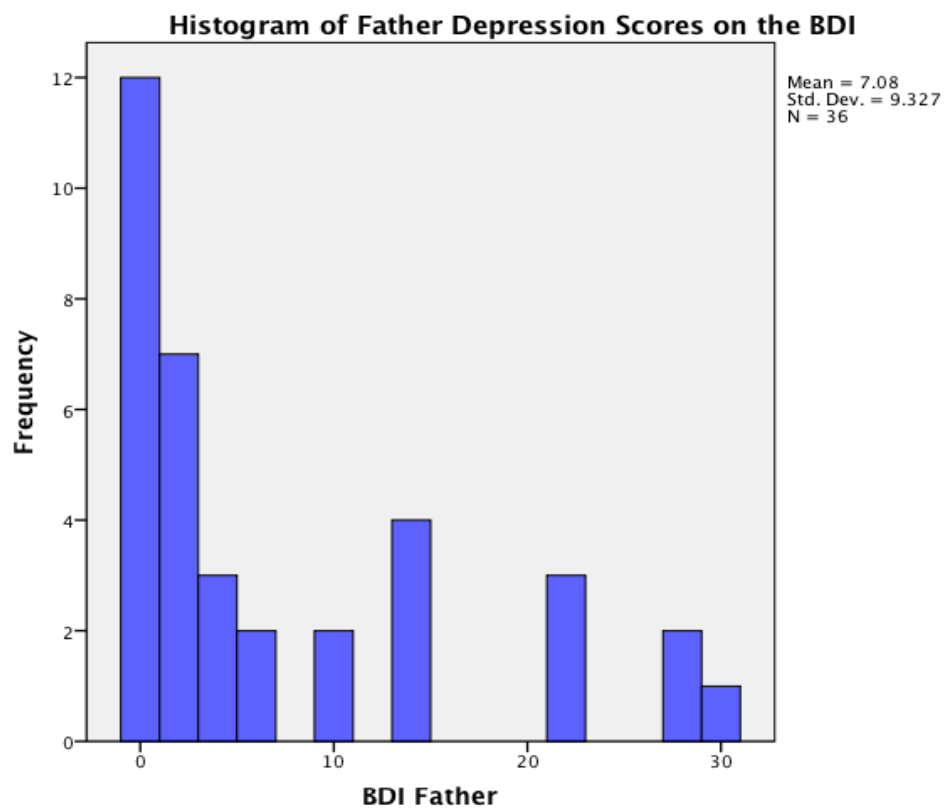
**Figure 4.2:** Histogram to Show the Spread of Father Age within the Research Sample



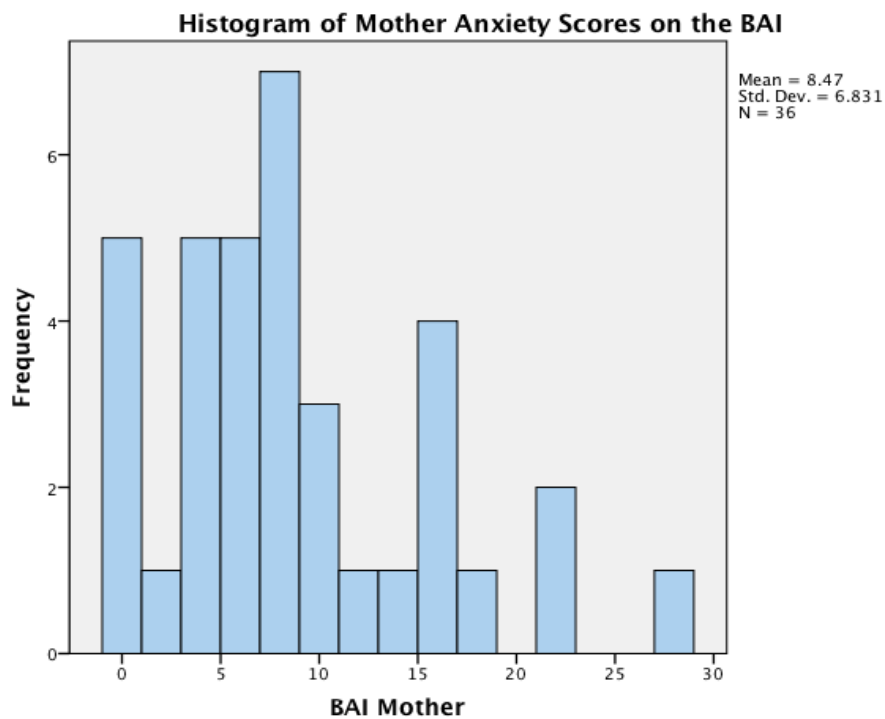
**Figure 4.3:** Histogram showing the distribution of Mother's scores on the Beck Depression Inventory



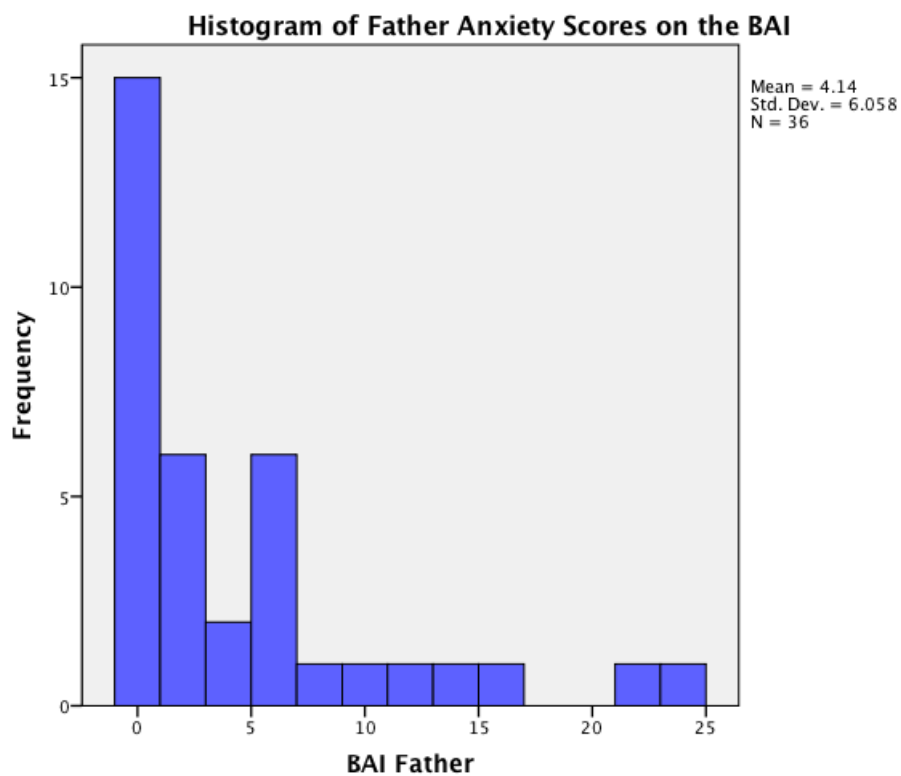
**Figure 4.4:** Histogram showing the distribution of father's scores on the BDI



**Figure 4.5:** Histogram Showing the Distribution of Mother Scores on the Beck Anxiety Inventory

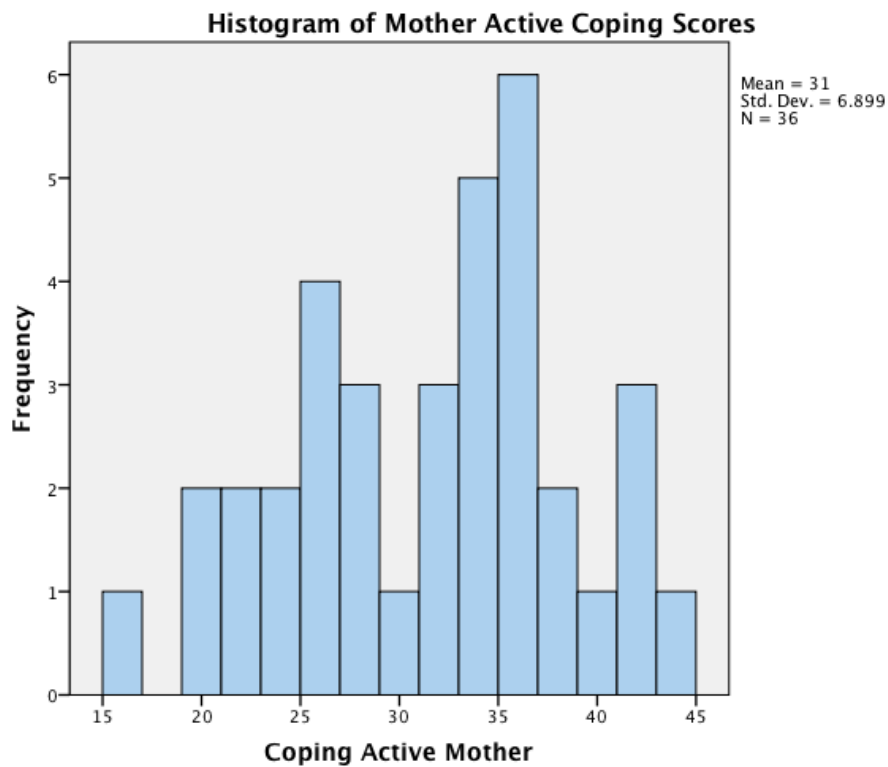


**Figure 4.6:** Box Plot Diagram Showing Outliers within Mother BAI Scores

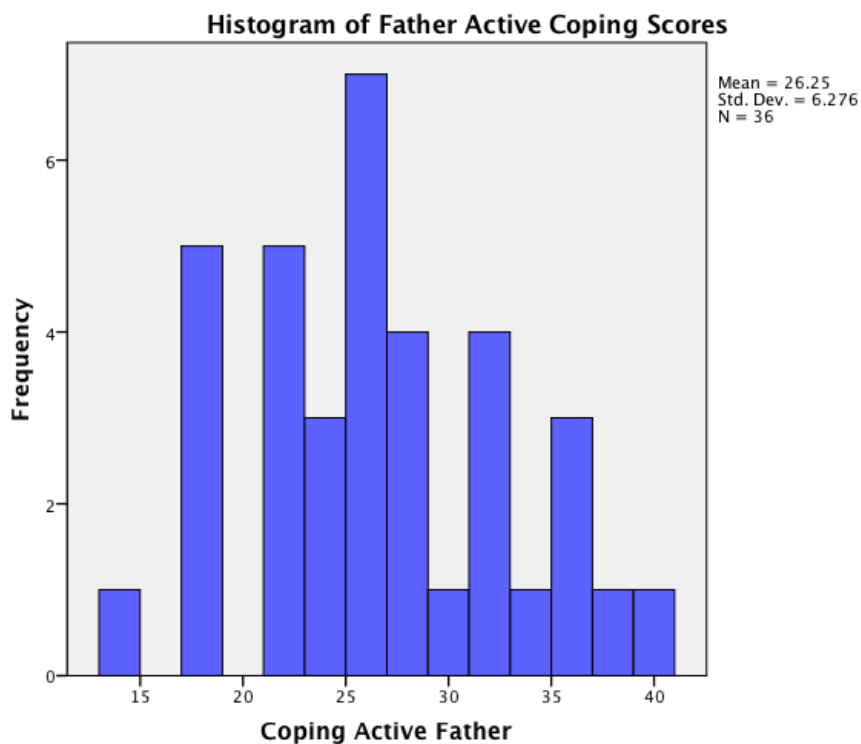




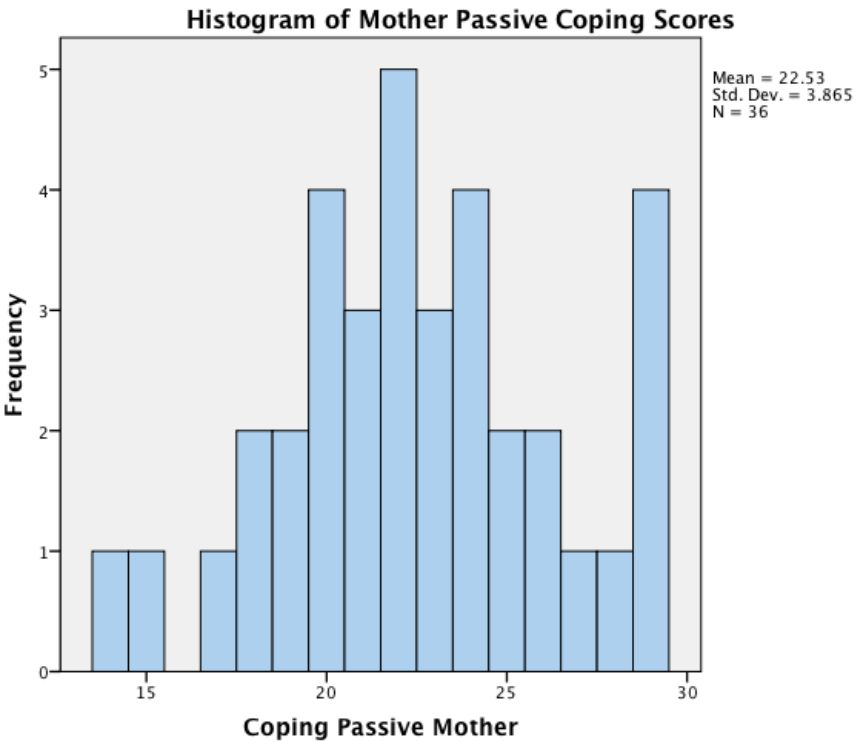
**Figure 4.7:** Histogram to Show the Distribution of Mother Active Coping Scores on the Brief COPE



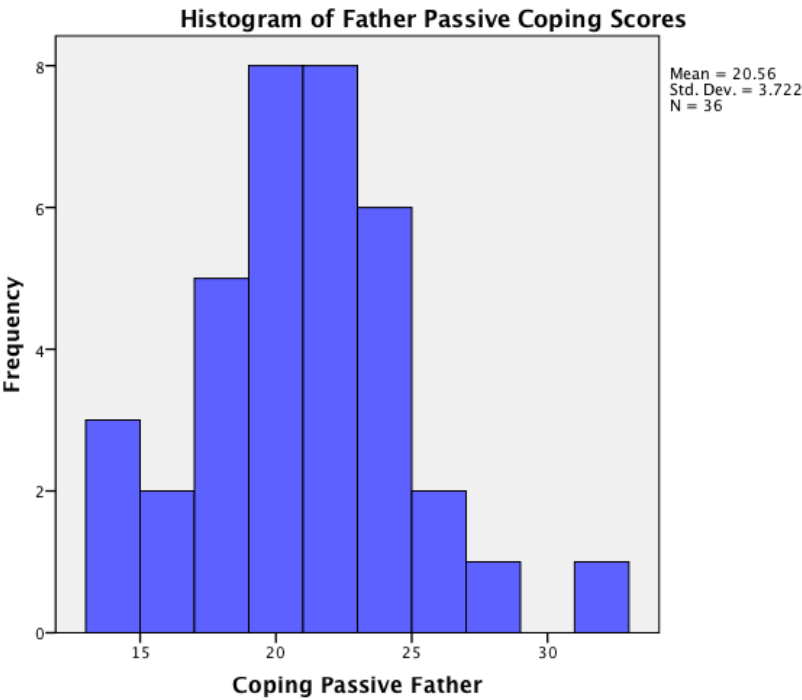
**Figure 4.8:** Histogram Showing the Distribution of Father Active Coping Scores on the Brief COPE



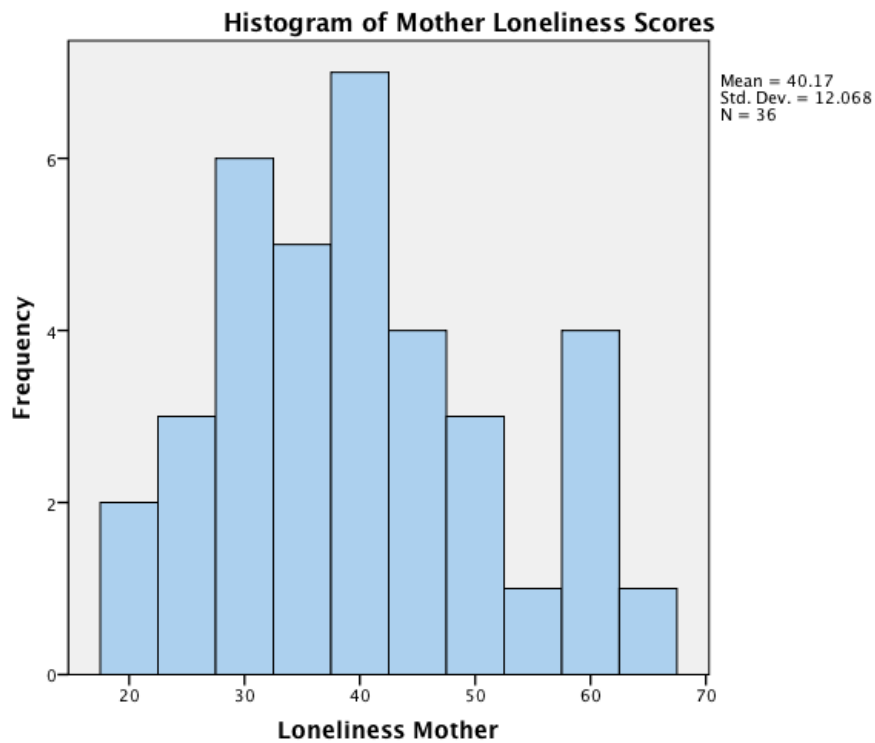
**Figure 4.9:** Histogram to Show the Distribution of Mother Passive Coping Scores on the Brief COPE



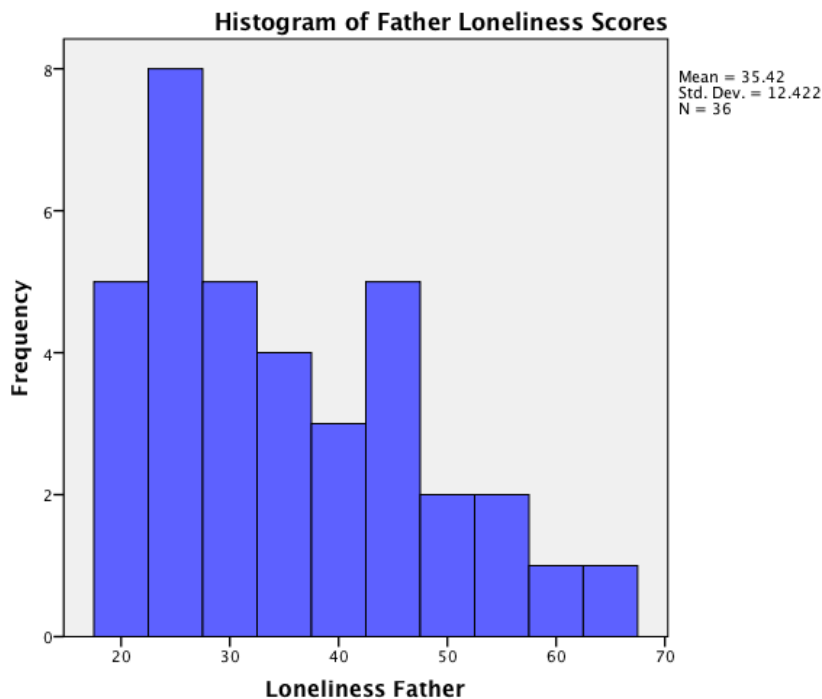
**Figure 4.10:** Histogram to Show the Distribution of Father Passive Coping Scores on the Brief COPE



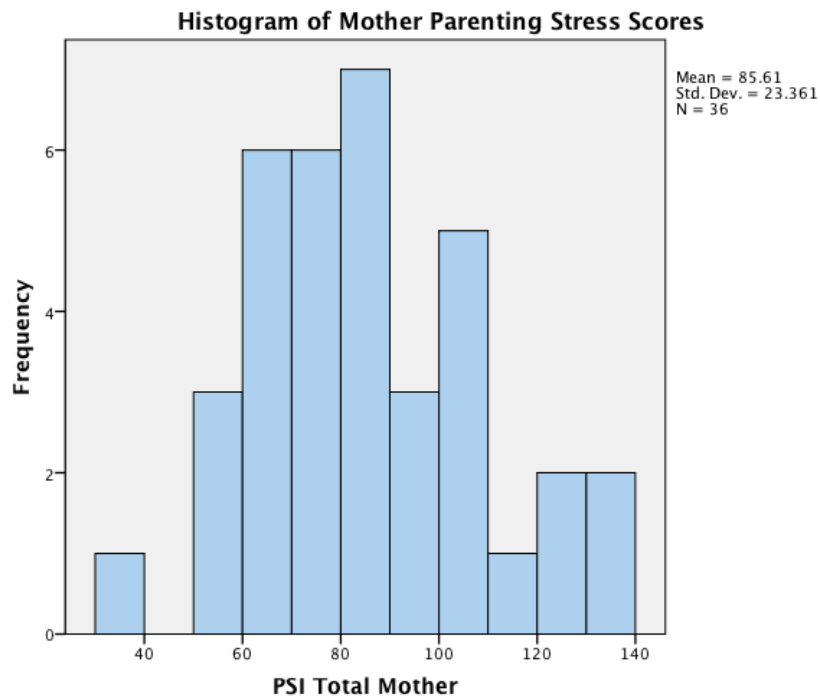
**Figure 4.11:** Histogram to Show the Distribution of Mother Loneliness Scores on the UCLA Loneliness Scale



**Figure 4.12:** Histogram to Show the Distribution of Father Loneliness scores on the UCLA Loneliness Scale



**Figure 4.13:** Histogram to Show the Distribution of Total Mother Parenting Stress Scores on the Parent Stress Index - SF



**Figure 4.14:** Histogram to Show the Distribution of Total Father Parenting Stress Scores on the Parent Stress Index - SF

